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ABSTRACT

The report describes tracking systems which address the need for early, reliable, and consistent identification and follow-up for children at risk for developmental disability. The systems, developed by 15 states that participated in the "Project Zero to Three" network, demonstrate how states may approach the linkages among prevention, early identification, and early intervention services. The efforts and strategies of the 15 states reflect the diversity of approaches, philosophies, systems, and state initiatives to identify infants at risk and to assist their families in locating and accessing early intervention and health care services. Discussed are goals of a tracking system, cost versus benefit of a tracking system, criteria for inclusion, criteria for discharge, instruments and techniques needed for optimal tracking and linkage to services, agency responsibility, and the role of parents. Appendices provide, for each of the 15 states, an outline of the system's purpose, a description, a discussion of issues/barriers, plans for the future, and sample forms. The 15 states presented include: Florida, Hawaii, Iowa, Kansas, Maine, Maryland, Massachusetts, New Jersey, New York, North Carolina, Ohio, Oregon, Texas, Utah, and Washington. Includes 15 references. (JDD)

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KEEPING TRACK

Tracking systems for high risk infants and young children

Second edition

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Keeping Track

Tracking systems for high risk infants and young children

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NATIONAL CENTER FOR CLINICAL INFANT PROGRAMS

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The first edition of *Keeping Track* grew out of issues raised in a meeting sponsored by Project Zero to Three in the summer of 1984. That meeting was planned by Eleanor Szanton and chaired by James Blackman, M.D. and Athleen Coyner R.N., F.A.A.N. Emily Schrag Fenichel prepared the text of *Keeping Track*, with comments from project and MCH agency staff and state participants.

Many thousands of copies of the first edition have been distributed through the National Maternal and Child Health Clearinghouse, and we appreciate their assistance in making so broad a dissemination possible.

By 1988, as supplies of the first edition of *Keeping Track* were dwindling, interest in tracking was growing, along with new legislative developments that were affecting the development and expansion of tracking systems. We were fortunate to have the assistance of Kathleen Schandl, a graduate student at Gallaudet University, in beginning the preparation of the second edition, and to have the support of the Bureau of Maternal and Child Health and Resources Development, notably Vince Hutchins, Merle McPherson, John Shwab and Diana Denboba. Updating and reprinting of *Keeping Track: Tracking Systems for Infants and Young Children* would not have been possible without their encouragement and funding. And we particularly appreciate the preparation and revision of appendix materials by Project Zero to Three liaisons and contributors whose names and locating information appear in the Appendix. All have been generous with their time and expertise, and their summaries are a central feature of this edition.

FOREWORD

In 1984 the National Center for Clinical Infant Programs published the first volume of "Keeping Track", highlighting the efforts of six states that were pioneers in the development of tracking programs for at risk infants, toddlers, and their families. In the intervening years the U.S. Surgeon General's initiatives on behalf of children with special health care needs, the passage of Public Law 99-457, and the Omnibus Budget Reconciliation Acts of 1985, 1986 and 1987 have focused attention on the need for an organized, collaborative effort to identify and monitor infants and toddlers with handicaps and at risk for developmental problems.

In 1989 the National Center is again presenting tracking systems which seek to address the need for early, reliable and consistent identification and follow up for children at risk for developmental disability. The efforts of fifteen states which participated in the Project Zero to Three network demonstrate how states may approach the linkages among prevention, early identification and early intervention services.

Such efforts are of particular importance as states and trust territories plan for the implementation of Public Law 99-457.Several requirements in the law have pressed state agencies to develop systems for tracking handicapped and at risk infants and toddlers. Under Section 676 (b), which outlines the fourteen *minimum components* of a statewide system of coordinated, comprehensive, multidisciplinary, interagency programs providing appropriate early intervention services to all handicapped infants and toddlers and their families, three components are particularly germane.

- The fifth required component is a *comprehensive child find system.* The system must provide opportunities for primary referral sources such as hospitals, physicians, or health departments to make referrals for evaluation and services. Major child find efforts currently implemented in each state must be coordinated, including both private and public agencies to assure the earliest possible identification and referral.
- The sixth component requires a *public awareness program* which directs its efforts towards the early identification of handicapped infants and toddlers. Public awareness through ongoing, continuous efforts must involve public agencies at the state and local levels, as well as private agencies, and advocacy groups.
- An additional component, the fourteenth, requires each state to have a *system for compiling data* on the numbers of handicapped infants and toddlers and their families. States must be able to report numbers of eligible infants in need of appropriate services, the numbers served, the types of services provided, and other information the Secretary of Education may require. In order to gather such data, states need to develop or refine management information systems. Information collected for the purposes of planning tends to be reported in the aggregate. For state planning, it is less relevant to know the status of an individual child (i.e. whether child "Mary Smith" is the process of being evaluated, receiving services, on a waiting list or has been discharged from the system) than to know how many children are receiving services, on a waiting list, and expected to need services next year.

The following pages attempt to share the state of the art in the development and refinement of tracking systems. No one state has the ideal system - rather, the development of a tracking system is a dynamic and ongoing process. None of the states finds its system complete. It is to their credit that none is yet satisfied.

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SUMMARY

The efforts and strategies of the fifteen states presented reflect the diversity of approaches, philosophies, systems, and state initiatives to identify infants at risk for poor health or developmental outcome and to assist their families in locating and accessing early intervention and health care services.

A universally available tracking system which embodies a continuum of care approach, providing early, continuous, and appropriate identification, follow-up, referral and monitoring for at risk and disabled infants and toddlers and their families remains a future vision.

However, the recognition for the *need* for such a system has grown. The individual *components* of a model system which could meet the needs of families at the community level, state administrators, legislators, planners and which can also provide the necessary information for federal agencies currently exist or are under development. The systems currently in place hold promise for a comprehensive approach which

- begins prenatally
- allows identification and enrollment at multiple timepoints
- provides information across multiple agencies and disciplines
- is sensitive to an agency's need for information balanced with a family's right to confidentiality
- provides data which are usable for program planning, development, evaluation and funding issues
- insures successful transition for child and family between services designed for a particular stage of development, or between agencies.

Many of the questions posed in the 1984 edition of *Keeping Track* remain relevant. New questions have emerged as result of new state and federal initiatives on behalf of children and their families. For those states that currently have tracking systems in place, modifications and revisions have occurred as a result of the lessons learned through implementation of the system. The original questions can provide a framework for evaluating the progress of the last five years, and promoting a vision for the future. These questions were:

1. What are realistic goals for a tracking system? Why is such a system worth time and effort?
2. What are the criteria for including a child in a tracking system? What ethical issues are involved? If a system is not limited to traditional categories of biological and established risk, to what degree and by what means can it include children at environmental risk for impaired psychosocial development?
3. What are the criteria for discharging a child from a tracking system? If development seems to be proceeding normally, how long should an at-risk child remain in the system?
4. What instruments and techniques are needed for optimal tracking and linkage to services?
5. What agency or group should have primary responsibility for a tracking system? How does the answer to this question affect the terminology used? Should responsibility shift as the child grows older? If so, how is such a transition best accomplished?
6. What is the role of the parent in a tracking system?

With the passage of Public Law 99-457, as well as other initiatives on behalf of children new questions regarding identification, tracking and follow-up have been identified.

- Given the interagency thrust of child find and identification under P.L. 99-457 how can tracking system data from one agency be shared and integrated with other agencies in a confidential manner?

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- How can states merge existing computerized data bases, which may not be compatible for tracking and follow up purposes?

- How can information from tracking systems best be utilized to meet federal reporting requirements for child count, yet still meet state information needs for planning, monitoring, and service provision?

- Should tracking systems only serve as prospective child find - or should a tracking system continue to follow children who have received an Individualized Family Service Plan (IFSP)

Definitive answers are not available. The ongoing lessons learned as states develop their systems have initiated further changes and revisions. **New Jersey** is in the process of revising the goals and objectives of the High Risk Infant Follow Up Program. **Iowa** has significantly reduced the information collected in the identification and intake phase of tracking, reducing the time and amount of paper work required to enroll an infant. **North Carolina's** High Priority Infant Program has undergone two major revisions since its inception in 1979. These revisions further delineated the eligibility criteria and the protocol for follow up services. A review of the original 1984 questions in light of the new concerns posed by Public Law 99-457 can begin to frame the key considerations for states seeking to develop tracking systems, or refining currently existing programs.

1. What are realistic goals for a tracking system? Why is such a system worth time and effort?

A tracking system of periodic and sequential monitoring and understanding of a child and family should be viewed as one of many essential elements in achieving the larger goal of fostering the health and development of disabled and at-risk children and their families. A tracking system may have several sets of related goals.

First, the tracking system should attempt to make certain that early identification leads to appropriate diagnosis and treatment, including early intervention services. The system should not only identify handicapped and at-risk children and families but also their needs; it can thus be a process which allows a community or state to see how close its services come to meeting those needs and to plan appropriately.

Further, Public Law 99-457 requires each state to develop a comprehensive system of child find as one of the fourteen minimum requirements required for implementation. Tracking systems which begin prenatally or identify infants in the newborn period can be viewed as prospective child find strategies - as they monitor infants who *may* require services in the future.

The **Maryland** Infants and Toddlers Program, Maryland State Department of Education and the Interagency Coordinating Council have defined the purpose of tracking as a statewide system for **collecting data,** both demographic and risk related, regarding infants and toddlers at risk of developmental delay to ensure appropriate intervention and to foster their health and development.

Several states, **New York, Kansas, and Massachusetts,** among them, view their existing or proposed tracking programs as key components in the comprehensive child find system for Public Law 99-457. To accomplish the coordination of multiple agencies may require additional resources and protocols for referral, or monitoring which may lead to further evaluation and services.

Secondly, the prevention focus of a tracking system remains an important characteristic. A tracking system for high risk infants can be seen as a means of secondary prevention, in the public health sense. Early identification of problems in a population at risk affords the opportunity for intervention to prevent, reduce or ameliorate the severity of difficulties for the child and family. **Florida's** Consolidated Registry system was developed in response to the requirements of the Florida Handicap Prevention Act of 1986. Information from three separate data sources, the Regional Perinatal Intensive Care Centers Program, the Consolidated Registry, and the Pre Kindergarten Handicapped Information Sharing System are linked to provide a mechanism for tracking infants and young children and services. While all three systems were developed to meet specific service and information needs, information from all three systems is available for service planners.

Third, a tracking system can increase knowledge and lead to informed planning. It can confirm, amend or expand current knowledge about the prevalence, etiology, incidence and outcome of a variety of conditions and disorders. It can also document the numbers of children and families needing and using services, thereby providing data which can be used to plan for the allocation of financial and human resources over both the short and long term. **Hawaii** envisions its future efforts in this direction as an integration of all existing tracking systems in order to accomplish this goal.

Maine utilizes a single data system to track services being provided to children and families - ranging from screening and evaluation services, to early intervention services including monitoring. Newborn screening is included. The use of a single data system provides an information management system that promotes local service coordination, as well as providing information required for state and federal reports. In addition, this approach permits longitudinal research, ongoing evaluation, and program monitoring.

Tracking system data can assist states in the development of statewide, comprehensive, coordinated, multi-disciplinary, interagency service delivery systems as part of their implementation of Public Law 99-457, in addition to the role it can play in child find.

Cost vs. Benefit of a Tracking System

Whether a tracking system is worth the time and effort expended by people and agencies who could be doing other things may be a question of perspective. Physicians in private practice may wonder whether doing the paperwork required by a tracking system makes sense if they fear that early intervention programs will result in the loss of their patients or are reluctant to "label" infants and young children with medical diagnostic classifications. Including primary care providers as well as tertiary center personnel in the planning of a tracking system is one way of being responsive to such concerns. Building fees for services rendered by primary care providers, especially pediatricians in private practice, into a tracking system and tying the system into the records already kept by practitioners may provide an immediate incentive to participation. Providing feedback to physicians and including them in the assessment and treatment of children and families may help them see the long-term worth of a tracking system.

The impact of a tracking system on families is also crucial to assessing its worth. Some parents may see such a system as a bureaucratic invention with little relation to ensuring the availability of appropriate services. They may feel money would be better spent publicizing and expanding services at the local level. A tracking system which "labels" children may alarm other parents. For many families, however, a tracking system provides reassurance and support for their own coping capacities.

North Carolina and **Washington** have addressed the labeling issue in part by using the term "high priority" to replace "high risk". Such a term may be less intimidating to families the agencies seek to serve.

Oregon currently has two pilot programs; one called the Infant Monitoring Program (IMP) and the Oregon Developmental Monitoring Program (ODMP). **New York's** program is simply called the Infant Health Assessment Program (IHAP).Generic names may reduce parental fears of labeling.

Some professionals and planners are concerned, however, that so many groups of children deserve urgent attention that it is inappropriate to use the term "high priority" for a single population. They suggest that "high risk" be used to describe those children who need specialized monitoring systems to identify emerging needs which can be met by appropriate programs.

Despite these concerns support for the concept of tracking has continued, and has become a major area of interest for policymakers. The National Governor's Association Report of the Task Force on Children (1989) recommended that states:

> "Develop a system to track high-risk infants from birth so case managers can effectively funnel these children into appropriate primary prevention services."

2. What are the criteria for including a child in a tracking system? If a system is not limited to traditional categories of biological and established risk, to what degree and by what means can it include children at environmental risk? What ethical issues are involved?

Tracking systems are designed to identify and follow infants who are felt to be at risk for poor health or delayed development. Operationally, "at risk" is used by various agencies to describe very different infants, i.e. infants who because of conditions of birth or home environment may be expected to show developmental problems, infants with identified conditions which are currently not impairing development but which may one day cause a problem; or infants who have been identified by someone as having a problem but have not been recognized as disabled by a program or agency (those on screening or waiting lists, for example).

The multiplicity of factors felt to place an infant or toddler at risk have often been grouped into the following categories:

a. Established risk, which refers to diagnosed disorders where the condition is known to affect development (e.g., the congenital anomalies associated with Down's syndrome).

b. Biological risk, which refers to prenatal, perinatal, and neonatal events that may affect development (e.g., prematurity, low birth weight, abnormal neurological findings).

c. Environmental risk, which refers to high-risk environmental influences that may affect development (e.g., parent substance abuse, adolescent parenting, psychiatric stress).

These categories are not exclusive. For example, a premature infant born to a teenage mother would be at risk due to both biological and environmental risk factors. An infant with these factors might be thought of as being doubly vulnerable for delayed development. Indeed it is possible for an infant to have risk factors in all three categories.No consensus yet exists on the best predictors of later difficulties in development. Currently states are using a variety of criteria for including infants and children in tracking systems. Low birthweight, hospitalization in a neonatal intensive care unit or birth to an adolescent mother are frequently used indicators. Recent research findings should encourage states to move beyond developing static lists of single risk indicators such as low birthweight or perinatal anoxia as possible predictors of poor health or developmental outcome. A dynamic model of risk which can address the psychologic, familial and interactional variables within a family unit has been proposed (Kochanek, 1988). Movement beyond traditional categories to an interactional, multivariate model of risk incorporating situations in which the risk to a child seems primarily environmental requires special sensitivity to families and possible involvement of other agencies which may be following these children, such as the mental health system. Many more states are considering environmental risk factors in tracking systems, but recognize that staff are understandably reluctant to report such determinations to parents, particularly when few appropriate intervention services are available.

Eligibility Criteria and Part H Services:

As states work towards the implementation of Public Law 99-457, Part H planners are struggling with coordinating criteria used for enrollment in a tracking system with the state's definition of children who are eligible for Part H services.

As one of the fourteen minimum components each state participating in Part H must develop a definition of developmental delay. In addition to serving infants and toddlers with handicaps who demonstrate developmental delays in cognitive, development, physical development including vision and hearing, language and speech development, psychosocial development or self help skills, states must provide part H services to infants who have physical or mental conditions which have a high probability of resulting in a developmental delay (Section 303.16(a)). Each state also has the option of extending services to infants and toddlers who are "at risk" for delayed development if early intervention services are *not* provided (Section 303.16(b)).

While guidance is provided as to what types of conditions or diagnoses might be categorized as "high probability" or "at risk" the factors noted are not inclusive and states can develop their own list of conditions or diagnoses. The most thorough examination of eligibility criteria which warrant further follow-up and tracking appears in the publication *Warning Signals* (Blackman, 1986). The collaborative product of a meeting supported by the Division of Maternal and Child Health and hosted by the National Center for Clinical Infant Programs contains recommendations for eligibility criteria to be used prior to hospital discharge as well as post discharge criteria.

Whatever definitions are developed by a state, coordination with tracking program criteria should ensure smooth transition from the tracking program to the service delivery system. It should be recognized that tracking system criteria can be much broader than the criteria for enrollment into services under Part H.

States which have had tracking systems in place prior to P.L. 99-457 may serve as models for other states. Broad tracking eligibility definitions in **Florida, Maine, Washington and Texas** currently include environmental risk factors, such as parental substance abuse or parental mental illness. This approach increases the potential number of enrollees dramatically, but permits the system to focus on children and needs not currently served—one of the main goals for a tracking system. Furthermore, systems which include both parental risk factors (including such psychosocial concerns identified at the time of childbirth) and infant criteria may be the most predictive of future developmental problems.

To a significant degree, eligibility criteria for tracking are influenced by a state's resources for follow up, and service provision. If only limited funds are available, a narrow range of eligibility criteria may be warranted. Eligibility criteria are also influenced by philosophical and political considerations.

Eligibility Criteria and Family Privacy

Risk factors such as parental substance abuse or emotional health can be critical, but raise sensitive issues of privacy. Little stigma is attached to some non-biological risk factors which tend to result in speech or communication problems or a mild degree of developmental delay. These include age of parent; parity (4th child or greater); death, for any reason, of a previously liveborn child; or any fetal death. Since the notion of any kind of "parental assessment" can be extremely threatening, it may not be feasible to perform such assessments, even though the information gained from the process may be considerably more predictive of the child's cognitive development than a mother's educational status alone.

Family privacy is not only an issue demanding sensitivity but also one of several important legal and ethical questions surrounding tracking systems. While any tracking system is voluntary, informed consent by parents should involve an understanding of the system's need to know particular kinds of information and the extent to which identification of problems is likely to result in the offer of services. Parents are often more willing to give data to a local health department than to a state agency. If tracking system information is to be used for needs assessment and planning, data can be aggregated wherever possible and names omitted. Informed consent by the parents might require agencies to share how and why the information will be used, who has access to it, and the potential impacts of information sharing.

In **Texas,** one of the two pilot tracking systems uses a parent questionnaire, available in English and Spanish, which asks the parent to identify infant behaviors, conditions, or characteristics which might place an infant at risk for developmental delay. This approach provides parents with an opportunity to share their concerns, as well as identifying concerns professionals may have.

Utah addresses confidentiality by taking the position that its tracking system is the guardian, not the owner, of information, with the responsibility for making sure that information is used for the child's benefit. In Utah, parents have tended to complain when agencies fail to share information with each other, confirming the sense of some meeting participants that "family privacy" may be misused as an excuse by agencies unwilling to share information for other reasons.

In **New York,** parental consent to participate is not required. Section 206.1J of the New York Sanitary Code grants the Department of Health the right to data collection. If parents wish to withdraw from the program for any reason, the case is closed at their request.

The **Massachusetts** High Risk Infant Identification System (HRIIS) is a legislatively mandated, statewide reporting system. Massachusetts has historically recognized the importance of a early identification of at risk infants. The Premature Infant Law of 1937 and subsequent laws over the last forty years have laid the groundwork for an active identification, reporting and data collection system.

Currently many tracking systems are administered within a single agency, generally state departments of health or social services. Rules, regulations and procedures are generally in place governing the type of amount of information that can be shared within the agency. The interagency nature of Public Law 99-457 raises new questions regarding sharing of confidential information between agencies that may not have prior arrangements for cross agency information sharing. Interagency agreements, or combined databases are possible solutions to this concern.

Ohio's Match II Project has created a merged database between the Department of Health and the Department of Mental Retardation/Developmental Disabilities. Through a SPRANS (Special Project of Regional and National Significance) grant the two agencies collaborated to develop a computerized mechanism to link information across agencies for identification, referral and tracking for children birth to six who are developmentally delayed or at risk of developmental delay.

3. What are the criteria for discharging a child from a tracking system?

A more positive way of phrasing this question might be to ask how we can assure adequate detection of problems and continuity of surveillance as children make the transition from systems tracking them from birth to age three (where original identification linkage to services often comes from a medical facility or health agency) to educationally oriented systems.

Transition issues are a major concern for states hoping to utilize their tracking systems as part of their comprehensive system of child find, one of the fourteen minimum components required by Public Law 99-457. Under Part H of the law, infants and toddlers at risk may receive services at the states discretion as part of the population eligible for early intervention services. Many of these children may not qualify for educationally based services at age 3. Should they continue to be tracked until age 5, or 6 or even until age 7 or 8? An additional concern is whether or not to track children currently in the service system even if an Individualized Family Service Plan (IFSP) has been developed.

For example, the tracking system in **Iowa** found that approximately 20 percent of the biologically at-risk infants born in a given year require special educational and therapeutic services in the early years of life. Of the remaining 80 percent, one fourth manifest emerging learning difficulties which warrant specialized assistance at school entry. This information is helpful to the education system, which must prepare for these children to receive appropriate services at the earliest time. Iowa's High Risk Infant Tracking System serves as a conduit for infants and young children with developmental needs to enter the educational system mandated to serve children from birth onward. Once a child has passed from Iowa's High Risk Infant Follow-up, Iowa's Special Education System takes the lead responsibility and the child is dropped from the High Risk Tracking System. Only those children who have not entered the education service system are followed until school age.

In **Maine,** screening, evaluation, and early intervention services are coordinated for children birth through five at the state level by the Interdepartmental Coordinating Committee for Preschool Handicapped Children. The information and data collection system in turn covers children until age five, and is designed to assist children and families with the transition into public school services.

A state's research and data base needs may be best served by tracking children and families, with their permission, well into the school years and, in some cases, until adulthood. Many at-risk children with conditions such as mental retardation, PKU or spina bifida may need services at particular periods, such as reaching reproductive age, or throughout their lifetimes. If tracking systems are to ensure the identification of infants requiring additional evaluation, or referral to services in the early years, arbitrary cutoff points at age two or three seem ill advised.

States may wish to explore approaches which utilize tracking system data for child identification and monitoring of health and developmental status, as well as a management information system regarding children in the service delivery system. This approach would provide child count information needed for state and federal requirements, as well as information needed for long range planning.

Expansion of a tracking system beyond three may promote the notion of a "seamless" service system which emphasizes importance of starting at birth and of a transition, rather than an end, of services at three. During the first three years of life, moreover, dropping any high-risk child already in a tracking system seems unwise: we simply know too little about the etiology and onset of developmental problems.

4. What instruments and techniques are needed for optimal tracking and linkage to services?

> "WANTED: Screening instruments. Inexpensive. Not so simple that children's problems will be missed, not so elaborate that expensive training or multiple/or highly experienced examiners are or will be necessary."

A want ad, rather than a recommendation for a specific screening instrument, may be a more accurate summary current thinking. For example, although screening tests such as the Denver Developmental Screening Test (DDST) are very widely used, they may be adequate for children under 30 months of age only when accompanied by a neurological examination. General screening tests of this sort have limitations in their usefulness after three years of age. They may miss many children who have more subtle disabilities of central processing. Thus, the instruments that are used must be appropriate for the age and developmental level of the child. If one is detecting mental retardation in a four-year-old, general screening tests may be adequate. If one is interested in problems related to memory, visual perception or language, more specific measures must be employed. The greater the degree of thoroughness with which screening is done, the fewer children (if resources remain constant) can be included in a tracking and screening program. The cost of having highly trained professionals screen at-risk children may be most cost efficient because they are able to supplement the DDST or other tools by assessing the quality of a child's performance and using their observational skills to analyze more parameters of development.

In **Oregon**, the Infant Monitoring Program (IMP) utilizes the expertise and observational abilities of parents as they complete developmental questionnaires covering communication, gross motor, fine motor, adaptive and personal-social areas. Standardization of the parent questionnaires is underway. In this way parents serve as "screeners" of their child, assisting professionals in identifying children who are in need of a comprehensive developmental assessment.

North Carolina has recently included intermittent parent-child assessment by the High Priority Infant Program Nurses, including instruments adapted from the Nursing Child Assessment Program (NCAST) such as the Feeding Teaching Scale (Barnard, 1978) as well as others.

The National Early Childhood Technical Assistance System (NEC*TAS) through the efforts of the Task Force on Screening and Assessment have provided an extensive overview of the key issues, considerations, and cautions related to screening and assessment. The recommendations of the Task Force are reported in *Screening and Assessment: Guidelines for Identifying Young Disabled and Developmentally Vulnerable Children and their Families* (1989).

Issues of eligibility for tracking or services cannot be separated from screening and assessment. States planning tracking systems will need to consider personnel, tools, and recommended protocols for screening and assessment as part of their overall plan.

5. What agency or group should have primary responsibility for a tracking system? How does the answer to this question affect the terminology used? Should responsibility shift as the child grows older?

The allocation of primary responsibility for tracking of disabled and at-risk children in the first three years of life will vary from state to state depending on the language of relevant legislation, the available sources of commitment, expertise and interest, or the designation of a lead agency for the implementation of Public Law 99-457.

A multiagency approach appears necessary even if a single agency accepts responsibility for the tracking system. Childfind activities occur in multiple agencies and information regarding the children participating in a tracking system may come from many different sources.

Agencies providing health services have historically been involved in the development of tracking systems. Given that hospitals are a natural point of entry to the tracking system, that most community referrals for tracking are likely to come from primary care providers or well child clinics, and that public health nurses may already be involved with the neediest families this has been a logical choice. Regardless of the agency charged with the primary responsibility for the tracking system, both health and developmental concerns can be emphasized in follow-up activities.

Several states have addressed interagency responsibilities for tracking. In **Kansas** the Governor's Subcommittee on Early Childhood Developmental Services proposed the development of an early identification, intervention and tracking system as part of the Kansas Plan for services to infants, preschool children and their families. The system is envisioned as a collaborative effort to be jointly funded by state Special Education, Health and Social Services and Rehabilitation Services.

Texas' Early Childhood Intervention (ECI) program which has responsibility for the pilot tracking projects is a legislatively mandated collaborative effort of the Department of Health, the Department of Mental Health and Mental Retardation, the Department of Human Resources, and the Texas Education Agency. This collaborative model facilitates interagency data sharing across agencies. Whichever agency takes the lead at various stages, consultation with other agencies concerned with infants, toddlers and their families is crucial.

States may elect to promote an interagency collaborative system by using a neutral agency, such as a university, and developmental disabilities council or consumer group to operate a tracking system. Such an organization might leave actual assessment to the health, human services or education departments and function rather as the manager of the tracking system and as advocate for the family and child. Legal mechanisms to ensure confidentiality would be an issue in such a system.

The Need for Common Terminology

When multiple agencies are involved in the administration or actual identification and follow-up of infants and toddlers at risk common terminology and agreement on eligibility criteria is essential.

In *Warning Signals* Blackman (1986) represents tracking systems as an information management tool, gathering data from multiple sources such as hospitals, health care providers, education, social services and vital records, through a wide variety of contact points for the multiple purposes of ensuring early identification and appropriate follow-up for both health and developmental concerns.

Viewed in this way, greater consensus on eligibility criteria and terminology might be facilitated.

Direct involvement of the key agencies in the development of the tracking system can facilitate consensus regarding terminology, and pave the way for ongoing information sharing.

Data Collection Issues for Tracking Systems

Some tracking programs may develop from pilot projects that used hand tabulated data. Others may begin in one agency and wish to expand to multiagency reporting. In either case, the need for integration with existing statewide information systems and computerization creates new challenges at both the state and local community level.

State agencies developing tracking systems will need data which provides information for ongoing evaluation and program monitoring, and cost accountability. Information linkage and sharing to meet these needs can be facilitated by interagency agreement, memoranda of understanding, or common computer registry forms to enhance cross agency communication.

Local agencies administering or participating in the tracking system will desire more specific information regarding the infants and toddlers served, services used, and other agency involvement.

Where the tracking system is viewed as part of a comprehensive child find system for Public Law 99-457 integration with existing state date bases, and program data collection is necessary. To meet the requirements cited in the law Component 14 requires "a system for compiling data on the numbers of handicapped infants and toddlers and their families in the State in need of appropriate early intervention services (which may be based on sampling of data), the numbers of such infants and toddlers and their families served, the types of services provided (which may be based on a sampling of data) and other information required by the Secretary" (Section 676(9)(14)).

States addressing the development of policies and procedures for Component 14 are struggling with the cost, time, and planning requirements of developing integrated computer systems.

Utah has invested years in the planning and development of a central, multiagency information system; the Central Registry for Handicapped Persons. The system is conceptualized as multipurpose system linking information served by social services, education and the Department of Health. The ultimate goal is for the registry to include all handicapped individuals in Utah whether served by either public or private agencies.

Not all states will have the opportunity for long term planning of their data and tracking systems. Many states have attempted to meet these challenges by engaging data specialists from the private sector. While public and private sector partnerships can, and have been successful, careful consideration is urged when exploring contractual arrangements. Expertise in information system management and design is not always readily available within a given state agency, or time constraints often make it necessary to consider private sector contractual arrangements.

As tracking systems, and their data collection efforts move beyond the pencil and paper stage to becoming a component in a management information service system the private sector has become increasingly involved and interested in this area. As in any contractual agreement, "Let the Buyer Beware."

6. What is the role of parents in the tracking system?

As highly concerned and knowledgeable individuals who play a critical role in advocating for needed services and in managing their child's use of care, parents have the right and responsibility to be involved in the design and implementation of a tracking system.

While the legal requirements of informed consent are determined on a state by state basis, and guided by the requirements of Public Law 99-457 parental consent to be included in a tracking system can signify an active choice rather than passive acquiescence. Tracking systems should encourage parents to see themselves as owners of information about their child, with the right to obtain all information entered into or generated by any data collection system, and with the authority to release date to themselves for review or to any specific agency which might be serving their child.

Sensitivity to cultural and ethnic variations are crucial for all states such as **Hawaii, New Jersey, Texas, Washington,** and **New York** which have a diverse population base or transient families. have recognized the need to develop materials for non-English speaking parents. True informed consent cannot be achieved without an exchange of information in the native language of the parent or guardian.

As states develop tracking systems, ongoing opportunities for parental involvement, support, and feedback can be built into all phases of system design, implementation, and modification. Key agency planners can accomplish this by soliciting the input of parents as systems are initially developed, and refined.

CONCLUSION

In our large and diverse nation, part of a complex and less than perfect world, state tracking systems of periodic and sequential surveillance of disabled and at-risk children may be an important step toward ensuring continuous and appropriate services to improve the health and developmental outcome of vulnerable infants and toddlers.

Given the recent passage of Public Law 99-457 and the momentum towards coordinated, community based systems of care promoted by the U.S. Surgeon General, the development and refinement of tracking systems has become a key agenda item for states. As the fifteen states represented in this volume have made clear, even states with more than a decade of experience in planning, implementing and refining follow-up systems do not yet have answers to questions as basic as the best criteria for inclusion in a tracking system or even the most appropriate instruments to use in screening and monitoring infant and young children. States now considering or planning a tracking system will not be followers along well-trodden paths as much as co-explorers of largely uncharted territory. Learning by doing, exploring the benefits and disadvantages of a variety of criteria, instruments, and administrative strategies, will continue to be a major means of accumulating knowledge about vulnerable children and their families, about the challenges they face in development, about the most effective means of helping them reach their full potential, and ultimately, about preventing disability.

Understanding and respect, trust and communication are critical to every aspect of successful tracking systems. It is important to remember that tracking systems tend to come into existence precisely because consumers, professionals and institutions so often feel unable to trust each other's data, capacity to respond to need, or terminology. Tracking systems need parents who are knowledgeable owners and reporters of information about their children; they need professionals and organizations committed to overcoming obstacles to understanding; they need state and federal governments willing to devote time and resources to a full exploration of etiology, prevention and remediation of biological and environmental risks to healthy development. As they grow, we may come closer to our goals.

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APPENDICES

FLORIDA

PURPOSE:

Tracking and data systems are developed to accomplish many different purposes. Florida currently has three systems, in various stages of development, which compile data on and provide a mechanism for tracking infants and young children and services. The Regional Perinatal Intensive Care Centers (RPICC) Program data system has been in existence since 1975. The Consolidated Registry was initiated in 1982. The Pre-Kindergarten Handicapped Information Sharing System (PKHISS) was authorized in 1987. Each of these systems was developed to meet a specific perceived service need and its development reflects those unique issues. A brief description of each of these systems is provided in the following sections.

DESCRIPTION:

Regional Perinatal Intensive Care Centers (RPICC) Program Data System

The RPICC Program is a comprehensive perinatal health care system, administered by Children's Medical Services in the Florida Department of Health and Rehabilitative Services, which provides high risk obstetrical care, neonatal intensive and convalescent care, and developmental evaluation and intervention services to infants discharged from neonatal intensive care units. These services are provided through a statewide regional network of nine (9) level three perinatal centers and seven (7) "step down" hospitals. In 1975 a computerized data system was developed to collect limited data on newborns served in the RPICC program. In 1977 data for the Developmental Evaluation component of the RPICC program became to be an integrated, comprehensive computerized data base management system to collect and correlate data from all three components of the RPICC program.

The RPICC data system has four major goals:

1. To evaluate RPICC program effectiveness and adequacy;
2. To track and evaluate the services and provided outcome for infants served in the RPICC neonatal intensive care units
3. To establish a monitoring and quality control system for high risk perinatal care;
4. To establish a RPICC program monitoring and fiscal management system.

The RPICC data system is designed as an online interactive system with visual computer terminals and/or personal computers (PCs) located at each of the provider sites, the program administrative office, and the data system base. The local computer terminals interact with the data mainframe system, although plans are underway to convert to a PC - mainframe back-up configuration. Confidentiality is assured via restricted access to the data system for data entry and retrieval of patient information.

The RPICC data system contains patient specific data in five areas: demographic; obstetrical; neonatal; developmental assessment and intervention services; and fiscal. This information is complied for each patient served in the RPICC program. Information for a mother-child dyad is linked as is the information from the Developmental Evaluation and Intervention component for a child linked with his neonatal history. Aggregate and/or patient specified data may be accessed and utilized by each specific component provider for their patients.

Information contained in the RPICC data system is used for various purposes:

1. Patient data are used to generate periodic routine reports for provider billing and for programmatic monitoring and quality reviews.
2. Aggregate patient data are used for programmatic reporting and program planning and budgeting.
3. Patient specific data may be accessed by providers to track developmental and intervention services for a child; to facilitate referral to needed services; and for case management.

The RPICC data system is a fully developed database management system which has undergone several modifications as user needs and technology have changed. The system's emphasis is now focusing on providing a data base for case management and tracking for infants being provided services through the Developmental and Intervention component of the program.

Consolidated Registry

The Florida Legislature in 1982 and 1983 established two new programs, both of which had, as major component, a registry of newborns. The primary purpose of the registries was the early identification, referral and tracking of children with cleft lip, cleft palate, or craniofacial anomalies, and children at risk for hearing loss. In implementing the requirements of these programs, Children's Medical Services in the Florida Department of Health and Rehabilitative Services decided to combine the registries and to add registry data for metabolic disorders and birth defects in general. The birth defects information was to include only those defects which could be identified at birth and was kept to a limited amount in order to encourage compliance with reporting requirements. The resulting system is known as the Consolidated Registry.

The consolidation was accomplished through an expansion of the Infant Metabolic Screening Program. The Infant Metabolic Screening forms submitted to the State Laboratory were revised. The data elements added were minimal - field for risk factors for hearing impairment and a file for coded birth defects. The codes are simplified (two characters) and include only generalized descriptions of bodily systems affected by the defect. Slightly more detail is required for craniofacial anomalies. This process made it possible to report infants very shortly after birth. Effective July 1, 1984, each hospital with live births in Florida was required to enter and report the presence or absence of birth defects and risk factors for hearing impairment on each infant.

The Consolidated Registry is a computerized data system which uses the State Laboratory data system to identify, register and refer infants who have been identified as having or being at risk or having one or more potentially disabling conditions. The Registry's systems design specifications were written to enable the Registry to function as a component of the Client Information System (CIS), which is the department's mainframe computer system.

The Consolidated Registry consists of the interlinking of three computer systems: (1) the Infant Metabolic Screening System of the State Laboratory, (2) the Consolidated Registry component of the Client Information System (CIS), and (3) the State Vital Statistics Data System. Normally, the laboratory slips are completed by the hospital nursery staff and sent to the State Laboratory. There, the laboratory staff key the demographic data into the Metabolic Screening System. Each night, a data tape from that system is created and forwarded to three HRS data centers for entry into the Consolidated Registry component of CIS. Meanwhile, the State Laboratory continues to process the slips. The results of these tests are entered into the Metabolic Screening System. A second tape is then generated to update the Registry.

Specified conditions identified initially include nine risk factors for hearing impairment, cleft lip, cleft palate, and craniofacial disorders; metabolic conditions, and other hereditary or congenial disorders. Special program components (i.e., hearing impairment, cleft lip/palate) have been developed within the consolidated registry to enable referral an follow-up services to be provided and tracked. This system is a secure system which only maintains the registration of an infant until the referral has been made or the treatment has been completed, depending on the specification of the program. As services are provided or follow-up contacts are made with the infant's family, the information on the Consolidated Registry is updated. The data on each infant are current, and program specific reports are generated.

Pre-Kindergarten Handicapped Information Sharing System (PKHISS)

PKHISS is intended to fulfill the requirements of the Florida Handicap Prevention Act of 1986. Its intent is to register at-risk and handicapped children ages 0-5 who are receiving, or may benefit from early intervention services. PHKISS is to be a part of a continuum of integrated services needed to identify, diagnose, and treat high-risk conditions in young children.

The current implementation of PKHISS operates a data base kept through a local education agency data base in the district where the child recieves services. The data base can provide information regarding;

1. The services the child receives and/or has requested;

2. The diagnoses made by physicians and clinicians of the child's handicapping conditions or risk factors;

3. The agencies that have provided services to the child;

4. The caseworkers, if any, who serve the child;

5. Release information defining to which state and federal agencies the parents have granted permission to share detailed information on the child;

6. Additional information on the child which may vary from district to district.

There are two versions of the program: one designed to run on a small personal computer and another to run under a multi-user operating system such as Unix. The microcomputer version is being developed at the Office of Early Intervention in the Florida Department of Education and is currently in its second revision. Thirteen pilots sites are designated for the microcomputer version thirteen pilot sites. The multi-user version is being developed at the University of Miami, Florida. Testing on this system is currently underway. The two versions are being developed in tandem to insure that the data bases created are compatible and will permit the sharing of information.The users of the system vary within each district. No concrete guidelines are given in the Handicap Prevention Act for location of the local data bases. At present most of the pilot sites are using the regional educational resource centers to house the local registry. The intended users are those individuals responsible for obtaining services for at-risk and handicapped children.

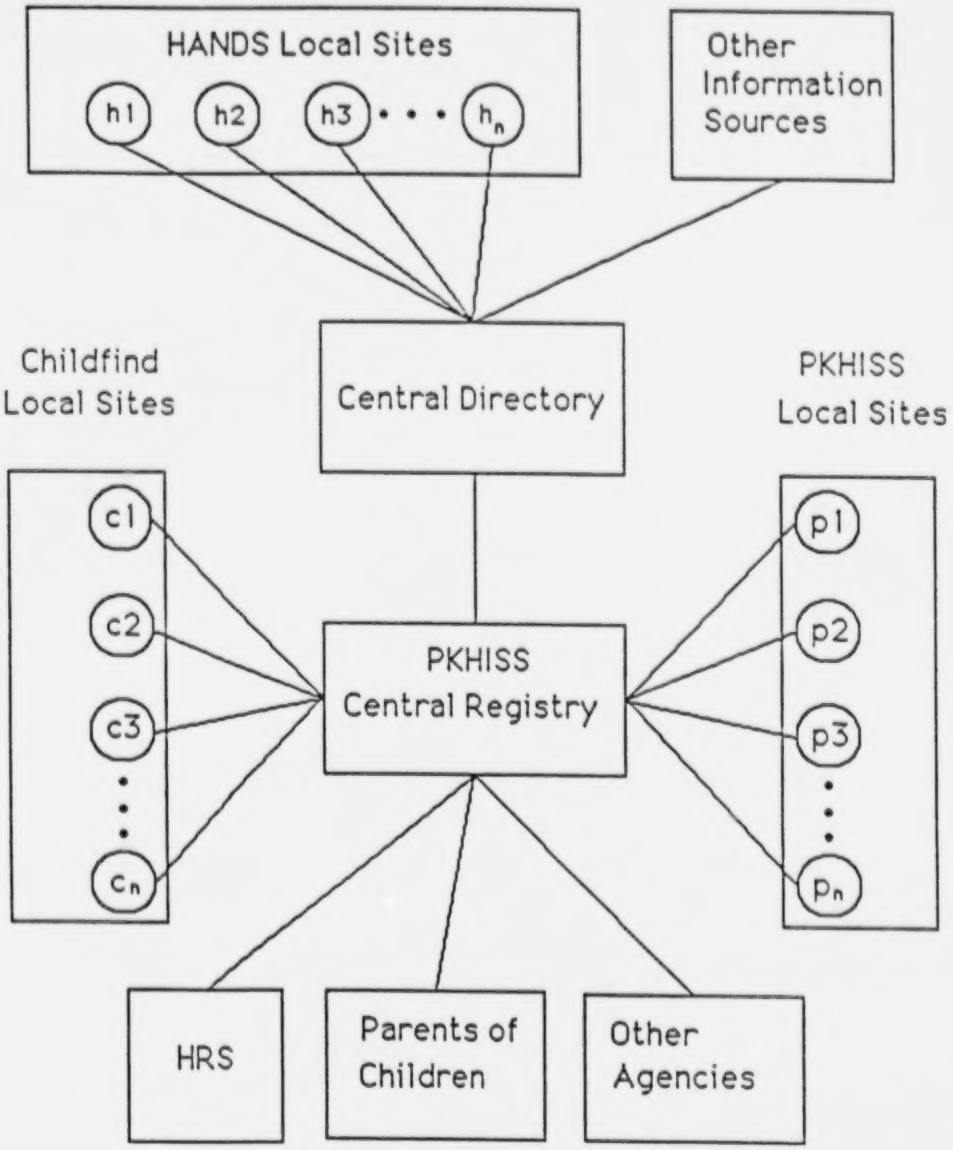
Data Bases kept in the local districts will be backed up to a Central Registry to allow for information sharing between agencies. The Central Registry will facilitate transfer of information about the child between agencies which have been granted access by the parents, and it will also be used to provide a more consistent delivery of services, facilitate movement of records from district to district, and help avoid duplicate entry of children in multiple districts.

FUTURE PLANS:

PKHISS is intended to fulfill the legislative intent defined in the Florida Handicap Prevention Act. It is also intended to help meet the dictates of Public Law 99-457 which require the development of a central directory of services for handicapped infants and toddlers, and a child find system designed to locate handicapped and at-risk infants and toddlers. Eventually the system is envisioned as a component of a large integrated system composed of a distributed data base covering all aspects of providing services to pre-kindergarten at-risk and handicapped children.

Proposed Information Flow Diagram for:

Florida Perkindergarten Information Sharing System,
Florida Human Assistance Network Direction Service,
Integrated with PL99-457.


HANDS Local Sites
h1
h2
h3
h_n
Other Information Sources
Childfind Local Sites
Central Directory
PKHISS Local Sites
c1
c2
c3
c_n
PKHISS Central Registry
p1
p2
p3
p_n
HRS
Parents of Children
Other Agencies

Florida Office of Early Intervention, DOE 10/27/88

(05)UNIQUE NUMBER ______
CENTER NUMBER __

CHILDREN'S MEDICAL SERVICES
STATE OF FLORIDA PERINATAL DATA SYSTEM
DEMOGRAPHIC RECORD FOR: CB___ NE___ DE___

(13)Today's Date:__.__.__
Time ___:___ am/pm

__.__.__.__ (09)Mother's Hosp. No.
(11)Mother's Name(last,first)
(052) (48)Child's Name(last,first)
__.__.__.__ (10)Child's RPICC No.

__.__.__ (12)Mother's Soc. Sec. No.
__ (14) Center Of Origin
Y / N (15)Infant Readmitted
Y / N (16)Mother Readmitted
__ (17)Experimental Group Code

(18)Resident Status:
1=Entrant
2=Unaccompanied Minor Entrant
3=Refugee
4=Unaccompanied Minor Refugee
5=Other Alien

(19)Mother's Marital Status
1=Married
2=Divorced
3=Separated
4=Never Married
5=Widowed
6=Other
7=Unknown

(20)Mother's Education
1 2 3 4 5 6
7 8 9 10 11 12
13 14 15 16=BD
17=BD+ 18=GD
19=Unknown
20=None

(21)Father's Education
1 2 3 4 5 6
7 8 9 10 11 12
13 14 15 16=BD
17=BD+ 18=GD
19=Unknown
20=None

(22)Household Gross Yearly Income
1= $0-$4,000
2= $4,001-$8,000
3= $8,001-$12,000
4= $12,001 or more
5= Unknown

Family Size
(24)Adults __
(25)Children__
(Do not include unborn child)

(26)Ethnic Origin
1=Black
2=White
3=Spanish surname
4=Other

(027,028,029,030,031)
(27 A-E) Family Public Assistance
1=None 5=CMS Perinatal Grant
2=MIC 6=AFDC
3=TP 7=Other Program
4=CMS 9=WIC

(032)
__________ (28) Medicaid Number
(033)
(29) Medicaid Status:
1= Not Available
2= Eligible
3= Not Eligible

__.__.__ (30) Child's Social Security Number

(31 A)Demographic Data On
1=Natural Parent
2=Adoptive Parent
3=Foster Parent
4=State Dependency

(31 B) Caretaker Now Is:
1=Natural Parent
2=Adoptive Parent
3=Foster Parent
4=State Dependency

___ (32)Mother's (036) Occupation Code
Y / N (33) Mother (037) Employed?

___ (34)(038) Father's Occupation Code
Y / N (35)(039) Father Employed?
__.__.__ (36)Year Month Day (040) Mother's Birthdate
__.__.__ (37)Year Month Day (041) Father's Birthdate Or Father's Age ____
__.__.__ (38)Year Month Day (042) Child's Birthdate

____ (39)(043) Birth Weight (gm)
__.__ (40)(044) Birth Length (cm)
__.__ (41)(045) Birth Head Circumference (cm)
(42)(046) Sex
1=Male
2=Female
3=Ambiguous
__ (43)(047) Weeks Gestation By History
__ (44)(048) Weeks Gestation By Exam

BIRTH PHYSICAL MEASUREMENTS

(049)(45)Number of Births For This Gestation
1 2 3 4 5 6
Write the number for more than 6 births __

(050)(46)If Multiple Birth, This child was born:
1st 2nd 3rd 4th
5th 6th 7th 8th __

(053)(49)Other Names of This Child

MOTHER'S MAILING & RESIDENCE ADDRESS (RE)

(0151)
(107)Mother's Name (Last,First)
(0152)
(108)Other Last Name of Mother
(0153)
(109)Street, Apt. No., Lot No., PO Box

(0154) (0156) (0155) (0157)
(110)City (111)State (112)Co. (113)Zip
(0158)
(114)Home Telephone Area Code/Number
(0159)
(115)Business Telephone Area Code/Number

Person Completing Form:____________ Title________

Demographic Form Revised 06/20/83

★ (167) UNIQUE NO.______
(096)

CHILDREN'S MEDICAL SERVICES
STATE OF FLORIDA PERINATAL PROGRAM OBSTETRICAL COMPONENT

Today's Date:__.__.__
Time:__:__ am/pm

★ __.__.__.__
(172)Mother's Hospital No.
(0100)

__.__.__.__
(173)Child's RPICC Number
(0101)

____
Mother's Name(last,first)

____
Child's Name(last,first)

MATERNAL DATA

✪ (099)
(170)
Mother's
Status Code
EL IE SP NN IC

✪ (0102)
(174)
Code No. for
Hospital of
Infant's Birth

✪ (0103)
(175)
Mother's
Gravida

(0104) (0105) (0106) (0107)
(176) (177) (178) (179)
Term Prem Abort Living
Mother's Parity
(Code Gravida & Parity 99 If Missing)

(0108)__.__.__
(180)
Year Month Day
Expected Date of
Confinement

(0110)__.__.__
(182)
Year Month Day
Date Declared
CMS Eligible

(0111)__.__.__
(183)
Year Month Day
Date Sponsorship
by CMS Began

(0112)__.__.__
(184)
Year Month Day
Date of First
Prenatal Visit

(0113)
(185)
Mother's
County of
Delivery

(0114)
(186)
No.Prenatal
Visits before
Delivery

(0115)
(187)
CMS Prenatal
Visits before
Delivery

(0116)
(188) Maternal Referral:
1=County Health Unit
2=Private Clinic, Phys.
3=Level 1,2 Hospital
4=Center Clinic
5=Other 6=None

(0117)
(189) Y / N
Birth In
Past Year?

(0118)
(190)____
Mother's
Residence
County

(0120)
(192) Mother's Discharge Status:
1=Discharged Home 4=Other
2=Expired, Autopsy
3=Expired,No Autopsy

(195) Mother's Blood Type:
1=Negative
2=Positive
3=Negative Du Pos

Item (194 A-D)(0122-0126) PRIOR PREGNANCY PROBLEM HISTORY

01 No Problems During Prior Pregnancy
02 Abnormal Delivery Presentation
03 Antepartum Hemorrhage
04 Cesarean Section
05 Diabetes
06 Eclampsia
07 Ectopic Pregnancy
08 Genetic Abnormality
09 Hypertension/Pre-eclampsia
10 Incompetent Cervix
11 Low Birth Weight/Preemie
12 Perinatal Death
14 Previous Child Dev. Delayed
15 Spontaneous Abortion
16 Uterine Dysfunction
17 Other Problem in Prior Pregnancy
18 No Information
19 No Prior Pregnancy
Other Diagnoses (Use ICD-9 Codes)
____ ____ ____

Item (207 A-E)(0144-0148) COMPLICATIONS OF CURRENT PREGNANCY AND PRENATAL HEALTH PROBLEMS

01 None
02 Acute/Recurrent KUB Infections
04 Anemia (Specify Hematocrit < 30)
__ Diabetes Class A=05 Class B=06; C=34; D=35; R=36 F=37
07 Diminished Renal Function/Kidney Disease
08 Psychological Disorders
09 Epilepsy/Seizure Disorders
10 Gastrointestinal Problems
11 Cardiovascular Disease (Organic)
12 Hemoglobinopathies
13 Hyperemesis with Ketonuria
14 Hypertension: Chronic (140+/90+)
15 Incompetent Cervix
16 Intrauterine Growth Retardation
17 Liver Problems
18 Mild Pre-Eclampsia
40 Eclampsia
41 (PROM)Prem. Rupture of Membranes >6 Hrs.Before Labor
42 Multiple Gestation (Twins, Triplets)
43 Obesity Weight >200 lbs.
44 Weight Gain >40 lbs. or <16 lbs.
45 Anorexia: Weight <100 lbs. Prior to Pregnancy
Other Diagnoses (Use ICD-9 Codes) ____ ____ ____
19 Multiparity (5+)
21 Post-Term (42+ Wks)
22 Pulmonary Dysfunction
23 Rh Sensitized/Irreg. Antibodies
24 Severe Pre-Eclampsia
25 Spontaneous Premature Labor (-36 Wks)
26 Substance Abuse (Not alcohol, tobacco)
27 Thyroid Disease
29 Vaginal Bleeding not Previa, Not Abruptio
30 Syphilis, Gonorrhea, Herpes
46 Other Venereal Infections
31 Viral Infections
32 Other Pregnancy Complications
33 No Information
47 Placenta Previa
48 Abruptio
49 Spontaneous Abortion
50 Collagen Vascular Disease
51 Pregnancy Induced Hypertension

Form Completed By:______________ Title________

Obstetrical Form Revised 06/20/83

CHILDREN'S MEDICAL SERVICES STATE OF FLORIDA PERINATAL PROGRAM
OBSTETRICAL COMPONENT

__-__-__-__ Mother's Hospital No.
______ Mother's Name(last,first)
______ Child's Name(last,first)
__-__-__-__ Child's RPICC Number

Item (208 A-E) ,0149-0153) ANTENATAL DRUGS

01 None
02 Alcohol
03 Antibiotics
04 Anticoagulants
05 Anticonvulsants
06 Antihypertensives
07 Antithyroid
08 Antituberculos
09 Cardiac
11 Diuretics
13 Hormones (Define)
14 Immunosuppressives

15 Insulin
16 Methadone
18 Glucocorticoids
19 Substance Abuse
20 Tobacco Use
21 Tocolytic Agents
22 Other Drugs
23 No Information
40 Rhogam
41 Psychotropic
42 Self-Prescribed Drugs

Item (209 A-J) (0154-0163) PRENATAL SPECIAL PROCEDURES AND INTERVENTIONS

01 None
02 Alpha-Fetoprotein(Blood or Amniotic Fluid)
03 Amniocentesis
04 Amnioscopy
05 Biochemical Analyses(Specify)
06 Cervical Suture
07 Chromosomal Study
08 Fetal Maturity Determination
09 Genetic Amniocentesis
10 Glucose Tolerance Test
11 Induced Abortion
13 Infectious Antibody Studies

14 Intrauterine Transfusion
15 Labor Inhibitors
16 Non-Stress Elec. Fetal Heart Rate
18 Nutritional Supplementation
19 Oxytocin Challenge Test
20 Photometric Anal. Amniotic Fluid
22 Ultrasound
23 XRay
24 Other Procedure, Intervention
25 No Information
40 Herpes Virus Screen
41 Surgery in Pregnancy

ITEM (210 A-E)(0164-0168) INTRAPARTUM PROBLEMS

01 No Intrapartum Problems
02 Abnormal Presentation
03 Abruption
04 Amnionitis
05 Arrested Progress of Labor
09 Eclampsia
10 Fetal Acidosis (lowest ph <7.20)
11 Fetal Distress by Tracing
12 Feto-Pelvic Disproportion
13 Herpes Progenitalis
15 Meconium Staining
16 Multiparity (5+)
17 Perinatal Death
40 Spontaneous Abortion

18 Placenta Previa
19 Polyhydramnios
20 Pre-Eclampsia
42 Pre-Eclampsia-Severe
21 Precipitous Labor (Less than 3hr)
23 Premature Rupture of Membranes
>24 Hrs. to dilation
24 Prolonged Labor
26 Shoulder Dystocia
27 Uterine Dysfunction
28 Other Intrapartum Problem
29 No Information
41 Premature Birth
__ Augmentation of Labor(code below)
Induction of Labor(code below)

ITEM (211 A-E)(0169-0173) INTRAPARTUM SPECIAL PROCEDURES AND INTERVENTIONS

01 No Special Procedure/Intervention

ANESTHESIA,ANALGESIA

- 02 No Anesthesia,Analgesia
- 40 General Anesthesia
- 04 Regional/Epidural/Caudal
- 05 Inhalation/Nitrous
- 41 Pudendal Block/Local
- 06 Narcotics
- 07 Narcotic Potentiators
- 08 Other Anesthesia,Analgesia
- 09 No Information on Anesthesia/Analgesia
- 10 Cesarean Section

11 Elec. Fetal Monitoring, Internal
12 Elec. Fetal Monitoring, External
13 Forceps: Mid
14 Forceps: Outlet
15 Scalp Blood Gases
16 Vacuum Extraction
17 X-Ray Pelvimetry
18 Other Procedure
19 No Information Procedures/Interv.
42 Augmentation of Labor
43 Induced Abortion
44 Induction of Labor

CHILDREN'S MEDICAL SERVICES STATE OF FLORIDA PERINATAL PROGRAM
OBSTETRICAL COMPONENT

__ __.__ __.__ __.__ __ Mother's Hospital No.

________ Mother's Name(last,first)

________ Child's Name(last,first)

__ __.__ __.__ __.__ __ Child's RPICC Number

Item (212 A-E)(0174-0178) POSTPARTUM PROCEDURES AND COMPLICATIONS UP TO SIX WEEKS

01 No Postpartum Procedure/Complication
02 Dilatation/Curretage
03 Eclampsia
04 Endometritis
05 Hemorrhage
06 Infant Death
40 Tubal Ligation
07 Maternal Death
08 Preeclampsia
09 Urinary Tract Infection
10 Other Postpartum Procedure/Comp.
11 No Information
41 Rhogam
42 Hysterectomy

INFANT DATA

(181) Y / N
Congenital
Anomalies

(0119)(191) Delivery Type
1=SVD
2=Elective Forceps
3=Other Forceps
4=Caesarean Section
5=Emergency C-Section
6=Breech Vaginal Del.
7=Vacuum Extraction

__ __.__ __.__ __
(193) (0121)
Year Month Day
Maternal Program
Discharge Date

(196)Delivery
Presentation
1=Breech
2-Vertex
3=Transverse Lie

(197) (0128)
Infant Was:
1=Inborn
2=Transferred

(0127+0129)(198) Disposition of Fetus
1=RNICC
2=Newborn
3=Intermediate Care
4=Expired/Autopsy
5=Expired/No Autopsy
6=Expired Before Labor
7=Expired During Labor
8=Expired/Time Unknown
9=Other Disposition

(0130,0131,0132,0133)
(199 A-D) (Circle up to 4)
Resuscitation at Birth
1=Supplemental O2
2=Bagged & Masked
3=Intubated
4=CPR Major
5=None

Ethnic Origin
1=Black
2=White
3=Spanish
Surname
4=Other

(0134,0135,0136,0137)
(200 A-D) (Circle up to 4)
Drugs Given Baby In
Delivery Suite
1=Bicarbonate
2=Epinephrine
3=Narcan
4=Other
5=None

__ __.__ __.__ __.__ __.
(201)(0138(
Infant's Hospital
Number in Hospital
of Birth

__ __ __ __ __ __ __ __ __ __
(202) (0139)
Infant's
Medicaid Number
Not Available___

(0140)/(0141/(0)
(203)/(204)/(205)
1 Min/5 Min/10 Min
Apgar Scores

Sex
1=Male
2=Female
3=Ambiguous

OBSTETRICAL COMPONENT ADDRESSES

REFERRAL AGENCY OR PHYSICIAN (MR)

____
(107)Last Name, First Name, Title
(0151)

____
(109)Street, Apt. No.,Lot No.,PO Box
(0153)

City	State	County	Zip Code
(110)	(111)	(112)	(113)
(0154)	(0156)	(0155)	(0157)

____
(115)Telephone Area Code and Number
(0159)

PROVIDER OF MATERNAL FOLLOW-UP CARE (MF)

____
(107)Last Name, First Name, Title
(0151)

____
(109)Street, Apt. No., Lot No., PO Box
(0153)

City	State	County	Zip Code
(110)	(111)	(112)	(113)
(0154)	(0156	(0155)	(0157)

____
(115)Telephone Area Code and Number
(0159)

NOTES:________

Signature of Obstetrician ________ Title ________ Form Revised 06/20/83

★ (116)UNIQUE NO.______
(06)

CHILDREN'S MEDICAL SERVICES
STATE OF FLORIDA PERINATAL PROGRAM, NEONATAL COMPONENT

Today's Date:__.__.__
Time:__:__ am/pm

__ __.__ __.__ __.__ __
Mother's Hospital No.

Mother's Name(last,first)

Child's Name(last,first)

__ __.__ __.__ __.__ __
★ (121)Child's RPICC No.
(009)

NEONATAL ADMITTING DATA

(010)
(122)
Mother's
Residence
County No.

(011)
(123)
Birth
County
Number

✪ (012)
(124)
Mother's
Gravida

(013) (014) (015) (016)
(125) (126) (127) (128)
Term Prem Abort Living
Mother's Parity
(Code 99 for Missing Gravida or Parity)

✪ (017).__ __.__ __
(129)
Year Month Day
Hospital
Admission Date

(018)
(130)
Code No.for
Hospital of
Birth

(019).__ __.__ __
(131)
Year Month Day
Date Declared CMS
Program Eligible

(133)(021)NICU
Admission Age
1= 0- 2 Hrs.
2= 3- 4 Hrs.
3= 5-12 Hrs.
4=13-24 Hrs.
5 = >24 Hrs.

(022) (023) (024)
(134) (135) (136)
Weight Length Head Circ.
Grams Centimeters
INFANT'S INITIAL ADMISSION
PHYSICAL MEASUREMENTS

✪ (008)
(119)
Child's
Status Code
EL IE SP NN

(137) Delivery
Presentation of
Child
1=Breech
2=Vertex
3=Transverse Lie

(138)(026) Primary Entry Mode
1=Inborn
2=Ambulance
3=Special Vehicle
4=Airplane
5=Helicopter
6=Private Auto
7=Maternal Trans.
8=Other
9=Military Aircraft

(139)(027) Delivery Type
1=SVD
2=ELF
3=Other Forceps
4=C-Section
5=XC-Section
6=Breech
7=Vacuum Extraction

(028)/(029)/____
(140) (141) (142)
1Min 5Min 10Min
Apgar Scores

NICU DISCHARGE DATA

(030)
(143) NEONATE DISCHARGED IN-HOUSE TO:
0=Unknown
1=Stepdown Care
2=Normal Nursery
3=Other Nursery
11=Died, Autopsied
12=Died, No Autopsy

(031) (032) (033)
(144) (145) (146)
Weight Length Head Circ.
Grams Centimeters
MEASUREMENTS AT
NICU DISCHARGE

✪ (034).__ __.__ __
(147)
Year Month Day
DATE OF DISCHARGE
FROM NICU

(035)
(148) DISCHARGE AGE
1= 0 - 2 Hrs.
2= 3 - 4 Hrs.
3= 5 -12 Hrs.
4=13 -24 Hrs.

CENTER DISCHARGE DATA

(149) NEONATE DISCHARGED OUTSIDE OUR CENTER TO:
0=Unknown
4=Other NICU
5=Stepdown Care
3=Normal Nursery
7=Other Nursery
8=Child's Home
9=Adoptive Home
10=Foster Care
11=Died, Autopsied
12=Died, No Autopsy
13=Institution
14=Other

(036) (037) (038)
(150) (151) (152)
Weight Length Head Circ.
Grams Centimeters
MEASUREMENTS AT DISCHARGE
FROM OUR CENTER

(039).__ __.__ __
(153)
Year Month Day
DATE OF DISCHARGE
FROM OUR CENTER

(040)
(154)
Outside
Hospital
Code No.

OUTSIDE HOSPITAL DISCHARGE DATA

(155) NEONATE DISCHARGED FROM OUTSIDE HOSPITAL TO:
0=Unknown
4=Other NICU
5=Stepdown Care
6=Normal Nursery
7=Other Nursery
8=Child's Home
9=Adoptive Home
10=Foster Care
11=Died, Autopsied
12=Died, No Autopsy
13=Institution
14=Other

____ ____ ____
(156) (157) (158)
Weight Length Head Circ.
Grams Centimeters
MEASUREMENTS AT DISCHARGE
FROM OUTSIDE HOSPITAL

__ __.__ __.__ __
(159)
Year Month Day
DATE OF DISCHARGE
FROM OUTSIDE
HOSPITAL

____
(160)
Outside
Hospital
Code No.

Form Completed By:____________________ Title__________

Neonatal Form Revised 06/20/83

UNIQUE NO.______

CHILDREN'S MEDICAL SERVICES STATE OF FLORIDA PERINATAL PROGRAM
NEONATAL COMPONENT

__.__.__.__	__.__.__.__	______________	______________
Mother's Hospital No.	Child's RPICC Number	Mother's Name(last,first)	Child's Name(last,first)

Item 161 (A-J) (041,042,043,044,045) DIAGNOSTIC AND THERAPEUTIC

01 None
02 Acute Volume Expansion
03 Brain Scan (CAT Scan)
04 Cardiac Catheterization
05 Chest Tube
06 Echocardiogram
07 Cranial Ultrasound
08 Exchange Transfusion
09 Parenteral Alimentation
13 Phototherapy

Patent Ductus Arteriosus(10-12)
- 10 Medical
- 11 Prostaglandin Inhibitors
- 12 Surgery

Respiratory Assistance(14-16)
- 14 Assisted Ventilation
- 15 Oxygen > 4 Hours
- 16 Continuous Distending Airway Pressure

17 Septic Work-up
18 Surgery, Major
19 Surgery, Minor
20 Umbilical Catheterization (Peripheral Artery Cath)
21 Other Diagnostic/Therapeutic Procedures

Drugs:
- 40 Priscoline
- 42 Antibiotics
- 41 Dopamine
- 43 Other

NOTES:______________________________

DISCHARGE DIAGNOSES ONLY: ENTER ICD-9 CODES

CONGENITAL ANOMALIES Item 162 (A-J)(051-055)		CONDITIONS ORIGINATING IN THE PERINATAL PERIOD Item 163 (A-T)(066-070)				SURGERY Item 164 (A-E)(091-095)	
_____	_____	_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____	_____	_____

COMMENTS, MEDICAL NOTES:______________________________

SIGNATURE OF EXAMINING PHYSICIAN:______________________ Date:__.__.__

NEONATAL AND COMPLEX SURGERY COMPONENT ADDRESSES

REFERRING PEDIATRICIAN (IR)

(0151)______________________
(107)Last Name, First Name, Title

(0153)______________________
(109)Street, Apt. No.,Lot No., PO Box

(0154)___(0156)___(0155)___(0157)___
City (110) State (111) County (112) Zip Code (113)

(0159)______________________
(115)Telephone Area Code and Number

INFANT FOLLOW-UP HEALTH CARE PROVIDER (IF)

(0151)______________________
(107)Last Name, First Name, Title

(0153)______________________
(109)Street, Apt. No.,Lot No.,PO Box

(0154)___(0156)___(0155)___(0157)___
City (110) State (111) County (112) Zip Code (113)

(0159)______________________
(115)Telephone Area Code and Number

Neonatal Form Revised 06/20/83

CHILDREN'S MEDICAL SERVICES
STATE OF FLORIDA PERINATAL PROGRAM DEVELOPMENTAL COMPONENT

______	__.__.__.__	__.__.__.__	____________	____________
(50)UNIQUE NO. (054)	(53)Mother's Hosp.No. (057)	(54)Child's RPICC No. (058)	Mother's Name(last,first)	Child's Name(last,first)

DEVELOPMENTAL EXAMINATION

___.___.___	___:___	__	__	____	ETHNIC ORIGIN	SEX
Year Month Day (55) EXAM DATE (059)	Hour:Mins.am/pm TIME OF DAY	Center of Follow-Up	Weeks Gestation	Grams BIRTH WEIGHT	1=Black 3=Sp.Surname 2=White 4=Other	1=Male 2=Female 3=Ambiguous

(58) Y / N Foster Care (062)

(59) Y / N Child Adopted (063)

(68) __ SPECIAL TREATMENT CODE

DEVELOPMENTAL TESTS:

(60)___ Bayley MDI (61)___ Bayley PDI (064,065)

(62)___ Stanford-Binet IQ (066)

SCORES: 1=No Delay 2=Questionable 3=Delayed

(63) 1 2 3 Denver Developmental Score (067)

(64) __ Test Code Name (65) 1 2 3 Score (068,069)

(66) __ Test Code Name (67) 1 2 3 Score (070,071)

DEVELOPMENTAL STATUS:

Scores: 1=Normal 2=Suspect 3=Abnormal

(073) (69) 1 2 3 Personal-Social

(074) (70) 1 2 3 Perceptual/Fine Motor

(075) (71) 1 2 3 Language

(076) (72) 1 2 3 Gross Motor

DEVELOPMENTAL NOTES, COMMENTS, OR IF ABNORMAL SPECIFY: Use ICD-9 Codes for Diagnoses

MEDICAL, NEUROLOGICAL, ALLIED HEALTH REFERRALS FOR DEVELOPMENT, EDUCATION, PERSONAL-SOCIAL CARE

Item 73 (A-E) (077,078,079,080,081)

01 Child Abuse Programs
02 Child Development Program
03 Children's Medical Services
04 Community Mental Health
05 Day Care
06 Dental Care
07 Developmental Services
08 Early Childhood Education
09 Easter Seals
10 Head Start
11 Infant Development Program
12 Language Therapy
13 Nutrition Counseling
14 Occupational Therapy
15 Physical Therapy
16 Protective Services
17 Public Health Dept.
18 Special Education
19 Speech and Hearing
20 SSI Div Blind Services
21 United Cerebral Palsy
22 United Way
23 WIC
24 Other
25 Other
26 Other
27 Hospital Clinic
28 DOE FDLRS
29 DOE PREP
30 DOE Other
31 Infant Hearing Screening
32 No Referral Made

NOTES, COMMENTS PERTAINING TO REFERRAL:

SIGNATURE OF DEVELOPMENTAL EXAMINER:____________________ Title:____________

(082)
(74) MEDICAL, NEUROLOGICAL AND DEVELOPMENTAL STATUS

1=Adequate for Age
2=At Risk for Delay
3=Certain Impairment(Give Diagnosis)

(083) (084)
(75) (76)
____ ____
Year Month

RETURN TO CLINIC FOR FURTHER EVALUATION

(085)
(77)

1=Lost To Follow-Up
2=Expired
4=Discharged
5=Transferred to Other Center

(086)
(78) __

Give Transfer Center Number

SIGNATURE OF DEVELOPMENTAL CLINIC DIRECTOR:____________________ Title:____________

(50)UNIQUE NO. (054)

STATE OF FLORIDA CHILDREN'S MEDICAL SERVICES PERINATAL PROGRAM
DEVELOPMENTAL COMPONENT

(53)Mother's Hosp.No. (057)	Mother's Name(last,first)	Child's Name(last,first)	(54)Child's RPICC No. (058)

MEDICAL EXAMINATION

Year Month Day Clinic Visit Date	Time am/pm	Grams BIRTH WEIGHT	ETHNIC ORIGIN: 1=Black 3=Sp.Surname 2=White 4=Other	Center of Follow-Up	SEX 1=Male 3=Ambiguous 2=Female	__.__ Temp. ____ Pulse

(087) (79)(cm) Height	(089) (81)(gm) Weight	(091) (83)(cm) Head Circum.	1=Yes/0=No (84) Medical Examination	(095)/(096) (87)/(88) Sys./Dia. Blood Pressure	Y / N (89)(097) Medications? List:________	Y / N (90)(098) Allergies? List:________	____ Weeks Gest. ____ Hct.

OLD 124

OVERALL MEDICAL EVALUATION: (86) WELL CHILD 1=Ab 2=Suspect 3=WNL (86) SICK CHILD 4=Ab 5=Suspect 6=WNL

Item 91 (A-L) (099-110)IMMUNIZATIONS: Check all that apply

2 month	4 month	6 month	15 month	18 month	4-6 yrs.
(A) __ DTP	(C) __ DTP	(E) __ DTP	(F) __ Measles (H) __ Rubella	(I) __ DTP	(K) __ DTP
(B) __ TOPV	(D) __ TOPV		(G) __ Mumps	(J) __ TOPV	(L) __ TOPV

Item 92 (A-M) (0111-123) CODE 1 ONLY IF A GENERAL MEDICAL ITEM IS ABNORMAL

(A) __ Head	(C) __ Eyes	(E) __ Throat	(G) __ Skin	(I) __ Heart	(K) __ Genitalia	(M) __ Spine
(B) __ Ears	(D) __ Neck	(F) __ Lymph	(H) __ Lungs	(J) __ Abdomen	(L) __ Extremities	

Medical Notes, Comments, Diagnoses (ICD-9 Codes)________________

OVERALL NEUROLOGICAL EVALUATION: (93) 1=Abnormal 2=Suspect 3-WNL

Item 94 (A-F) (0125-130)

CODE 1 ONLY IF ABNORMAL	(A) __Cranial Nerves	(C) __Motor/Tone	(E) __Coordination
	(B) __Reflexes	(D) __Activity & Behavior	(F) __Seizure Medication

If on Seizure Medications, explain:________________

Comments, Neurological notes; If Abnormal or Suspect, specify:________________

SENSORY SCREENING: (0131) _(95) Hearing (0132) _(96) Vision 1 Normal 2 Suspect 3 Impaired 4 Deaf/Blind

(0133)
_(97) Y / N REFERRALS: (Codes 01-31 from Developmental Exam)________________

(0134-138)
Item 98 (A-E) ICD-9 Codes or Code Numbers 001-155 from list
(A)____ (B)____ (C)____ (D)____ (E)____

(0139-144)
Item 99 (A-G) Number of Hospitalizations
__(A)Birth-6Mos. __ (C)13-24Mos. __(E)37-48Mos.
__(B)7-12Mos. __ (D)25-36Mos. __(F)49-60Mos.

REFERRING PHYSICIAN (DR)	DEVELOPMENTAL FOLLOW-UP PHYSICIAN (DF)
(0151)	(0151)
(107) Last Name, First, Title	(107) Last Name, First, Title
(0153)	(0153)
(109) Street, Apt. No., Lot, PO Box	(109) Street, Apt. No., Lot, PO Box
(0154)____(0156)__(0155)__(0157)__	(0154)____(0156)__(0155)__(0157)__
(110) (111) (112) (113) City State County Zip Code	(110) (111) (112) (113) City State County Zip Code
(115) Area Code and Telephone Number	(115) Area Code and Telephone Number
(0159)	(0159)

SIGNATURE AND TITLE OF EXAMINING PHYSICIAN ________________

Form Revised 06/20/83

★(213)UNIQUE NO.______

CHILDREN'S MEDICAL SERVICES
STATE OF FLORIDA PERINATAL DATA SYSTEM

Today's Date:__.__.__
Time:__:__ am/pm

★(216) FISCAL RECORD FOR: NE__ OB__ SU__ DC__ DE__

★__.__.__.__ (217) Mother's Hospital No.	__.__.__.__ (218) Child's RPICC Number	____________ Mother's Name(Last,First)	____________ Child's Name(Last,First)

★(219) EL=Eligible IE=Insurance Eligible SP=Sponsored NN=Noneligible IC=Intensive Care Mom

---

$(0186)________ (220) Patient's Hospital Charges	(0190) __.__.__ (224)Year Month Day Hospital Admission	(0191) __.__.__ (225)Year Month Day Hospital Discharge
$(0187)________ (221)Patient's Physician Charges	(0192) __.__.__ (226)Year Month Day Charges Began	(0193) __.__.__ (227)Year Month Day Charges Ended
$(0188)________ (222) Patient's Other Professional Consultations, Fees	(0194) __.__.__ (228)Year Month Day Charges Began	(0195) __.__.__ (229)Year Month Day Charges Ended
$(0189)________ (223) Obstetrical Outpatient Charges	__.__.__ (230)Year Month Day Charges Began	(0197) __.__.__ (231)Year Month Day Charges Ended
$________ (223) Outgoing Transport Charges	__.__.__ (230)Year Month Day Date of Outgoing Transport	(239) OUTGOING TRANSPORT MODE: 2=In Utero 6=Special Vehicle 3=Ambulance 7=Private Auto 4=Helicopter 8=Other Mode 5=Airplane 9=Military Aircraft
$(199)________ (233) Incoming Transport Charges	__.__.__ ( )Year Month Day Date of Incoming Transport	(0198) (232) INCOMING TRANSPORT MODE: 2=In Utero 6=Special Vehicle 3=Ambulance 7=Private Auto 4=Helicopter 8=Other Mode 5=Airplane 9=Military Aircraft

(0200,0201,0202,0203,0204)
ITEMS (234 A-E) FUNDING
Circle All That Apply:

1=CMS Perinatal Grant	5=Major Medical
2=CMS Non-Grant	6=Insurance
3=CMS Complex Surgery	7=Self
4=Florida Medicaid	8=Other

THIRD PARTY PAYORS:
(0205)(235) Y / N Hospital Charges
(0206)(236) Y / N Physician Charges
(0207)(237) Y / N Profess. Consults/Fees
(0208)(238) Y / N Outpatient Charges

Form Prepared By:____________ Title ________

Form Revised 06/20/83

INFANT SCREENING PROGRAM

CODES FOR HRS FORM 677

HEARING RISK FACTORS

Codes

1 **Family History** - Family history of hearing impairment prior to age six (6).

2 **TORCHS** - Documented or Suspect congenital Perinatal Infection:

Toxoplasmosis
Other Agents
Rubella
Cytomegalovirus
Herpes
Syphilis

3 **Bilirubin** - Unconjugated serum bilirubin:

-more than 15 mg/dl for term (37 weeks)
-more than 12 mg/dl for pre-term (less than 37 weeks)

4 **Low APGAR** - Score of 6 or less at 5 minutes.

5 **Neonatal Sepsis/Meningitis**

6 **Intraventricular Hemorrhage** - Documented or suspect intraventricular hemorrhage

7 **Seizures** - Seizures or other disorders of the CNS

9 **NO RISK FACTORS NOTED**

BIRTH DEFECTS

Codes

A1	Cleft Lip
A2	Cleft Palate
A3	Cleft Lip and Palate
A9	Other Craniofacial Defects
B1	Spina Bifida
B9	Other Nervous System Defects
C1	Down Syndrome
C9	Other Chromosomal Defect
E9	Eye Defect
G9	Gastrointestinal Defect
H9	Congenital Heart Defect
M9	Musculoskeletal Defect - (not involving head or spinal cord)
P9	Genital Organ Defect
R9	Respiratory Defect
U9	Urinary System Defect
X9	Other or Unspecified Defect
Z9	**NO BIRTH DEFECT NOTED**

Please enter a code for any infant with an **obvious** defect at birth or for any infant with a **suspect or confirmed** condition.

HRS Form 677, Oct. 83
(Obsoletes ALL Previous Editions)

DO NOT TEAR APART OR REMOVE CARBON

Infant's Name LAST _______________ FIRST _______________ MI ____ SEX ____ RACE ____

Mother (LAST,FIRST) ______________________ Father (LAST,FIRST) ______________________

Home Address STREET AND NUMBER ______ CITY ______ STATE ______ ZIP ______ COUNTY ______

Telephone Number where Parent can be reached ______________________

Birth Date,Time M M D D Y Y ______

Hospital of Birth ______________ Infant's M.R.# ______________

1st Feed Date,Time ______________

Infant's Physician ______________ Physician's Telephone # ______________

Collection Date,Time ______________

Birth Weight ______________ ☐ Full Term ☐ Premature NICU: ☐ YES ☐ NO

Transfused Date,Time ______________

Risk Factors ______ ______ ______

Birth Defects ______ ______ ______ ______

Antibiotics ______________

Mail Report To:
Hospital
CHU
Physician ______________________

Address ______________________

City ______________ STATE ______ ZIP ______

Hospital Lab # ______________

☐ First Specimen

☐ Repeat (Indicate Tests) ______________

State of Florida • Dept. of Health and Rehabilitative Services
Office of Laboratory Services

Infant Screening
Metabolic Disorders
HRS Form 677, DEC. 86
Replaces ALL Previous Editions

(Do Not Write Here)

LABORATORY RESULTS

PKU ______________ mg%

T4 ______________ μg/dl

TSH ______________ μIU/ml

Galactosemia: ☐ Normal
☐ Zero Fluorescence
☐ Partial Fluorescence
☐ Previously Tested Normal
☐ Unsatisfactory

HAWAII

HISTORY:

Hawaii envisions the development of a comprehensive tracking system which begins, prenatally, includes identification, monitoring, and assurance of contact and intervention by appropriate providers with optimal intensity and frequency. The envisioned system should function across agencies and across age groups, in order to assure successful transition into the next stage for the child and family; it should be built on trust that the information will be appropriately used. Given this, the data are then available for program planning, development and funding issues.

While some components of the system are already in place, these remain future goals. At present, Hawaii is a long way from a comprehensive coordinated system.

DESCRIPTIONS:

Tracking and follow up programs that are currently implemented in Hawaii cover a variety of target populations and needs. Integration of the various existing programs is a goal Hawaii is working towards.

NEONATAL INTENSIVE CARE FOLLOW-UP PROGRAM

This program provides certain higher and highest risk graduates of the neonatal Intensive Care Unit (ICU) nursery specific and regular evaluation in the Child Development Clinic of the tertiary hospital, re-evaluation through age 5 and assurance for appropriate interventions statewide. These "graduates" are also followed by Public Health Nurses, who are part of the hospital's discharge conferences, into the community, with assistance provided by the nurse to the family to assure timely and appropriate interventions. The families are followed by the public health nurse until she and parents feel things are going smoothly. The case may then be closed.

CHILD STUDY UNIT AND CHILD/INFANT DEVELOPMENT PROGRAMS:

As part of the Department of Health and the Developmental Disabilities Division, the Child Study Unit assesses and assures complete, thorough, multidisciplinary, diagnostic evaluations on any infant, toddler or child who is suspected of having a developmental delay, Then, with the family, an individual service plan is developed and interventions sought as appropriate. The Infant and Child Development Programs in all areas of our state assume the intervention responsibilities, then, for the most part. These programs follow through with referrals to other appropriate programs, if the Development PRogram is not what is needed. Further follow-up after referral to other agencies does not occur.

CHILDREN WITH SPECIAL HEALTH NEEDS SERVICES:

This program follows their clients who fit medical and financial eligibility criteria over the years. The multidisciplinary support services, in addition to the medical services purchased, are provided to clients and families, until "discharge". Other services provided here include the Newborn Screening Program which identifies, intervenes and follows infants with phenylketonuria and hypothyroidism into adult life.

OTHER PROGRAMS FOCUSING ON SPECIFIC TARGET GROUPS:

Hawaii has two home visitor programs which provide outreach, identification, assessment and follow-up of certain populations of at risk families and their children. One is the Family Support Home Visitor Program which screens families while in the hospital at the time of birth. This program is available across many areas of the state. Follow up occurs in the home for all those families identified as at risk for child abuse and neglect and will occur for as many years as necessary up to 5 years. Another program, run by Kamehameha School/Bishop Estate, provides home visitors, parenting education, child development instruction, nutrition and health care instruction,etc. for Hawaiian and part-Hawaiian families early in pregnancy and continuing until the youngster enters a "4-year-old" preschool. This program focuses on psychosocial-environmental risk for developmental delay, tracking their families only through to regular school age.

The previously mentioned programs are all involved in tracking their own clients and families, although they do so only as long as they remain on their active case loads. Most of these programs make an effort to assure that other agencies become involved as other interventions are needed and transitions are made. The follow up is not yet consistent, nor assured across agencies, services, or age groups. Each program constitutes a piece of an incomplete statewide system.

NEW PROGRAMS:

The Regional Perinatal Program has developed proposed standards of care covering the prenatal, perinatal and infant period, including the need for special attention to any high risk conditions identified. These proposed standards are being distributed to community health care providers along with education and training their importance and utility in providing comprehensive care. A goal of the program is to encourage pediatricians, to be more effective medical and health-care managers as part of community based interdisciplinary teams.

Other beginning programs include: 1) a Birth Defects Monitoring Program, which will review hospital records of children through at least their first birthday. A follow-up component is anticipated. 2) a Maternal Serum Alpha Fetoprotein education, intervention and data collection program which will soon be underway. Hawaii has also adopted the US Standard Birth Certificate which will assist in data collection regarding infants at risk.

ISSUES/BARRIERS:

The development of programs to address the needs of specific groups has resulted in a fragmented tracking system. Problems with confidentiality laws and regulations are additional barriers to be overcome in the development of a comprehensive coordinated system. At the present time an additional challenge is found in working with Hawaii's state management information system. The system is currently in transition and needs expansion and improvement to provide a central, automated client record system.

FUTURE PLANS:

Hawaii has many challenges ahead as providers and consumers begin to develop a comprehensive, coordinated tracking system which utilizes the components already in place. Plans are currently under development to develop a single point of entry for all services. A comprehensive database of clients using any state funded service would be developed. In the future families will be able to access state funded services through one "gate" avoiding duplication of intake procedures. This system would be available to all identified families who wish to receive state funded services and wuld ideally extend across services, agencies, disciplines and diagnoses. The information held in the system must evolve with the family's participation, approval and control.

IOWA

The Iowa High Risk Infant Follow-up Program was established in 1978 to identify the developmental and special health needs of infants at developmental risk, to initiate referrals to appropriate agencies if definitive evaluation and remediation are required, to offer support to parents, and to facilitate the family's use of community resources.

PURPOSE:

The Iowa High Risk Follow-up Program has six components which reflect the goals of the program.

1. Implementing a statewide process for identifying and tracking infants and children whose births were associated with specific factors that put them at risk for later manifesting developmental disorders;
2. Determining reliable, valid, and cost-effective methods for identifying such children and their developmental needs as early as possible;
3. Helping the primary health care providers coordinate the service referral process for children and families with identified needs;
4. Determining the training needs and providing educational programs for personnel involved in identifying and caring for such children;
5. Collecting, storing, analyzing, and interpreting the data emanating from the program; and
6. Disseminating the results of these findings to other states or regional comprehensive child health service systems.

DESCRIPTION:

Much has been learned about tracking during the past ten years as nearly 5000 children have been served. We believe that we have achieved our goal of establishing a working early identification, referral, and support system for the group for whom the program was designed. Pediatric Nurse Practitioners, supported by public and private hospitals and by Title V funds through the state program for children with special health needs, administer a developmental screening test and physical examination at ages 4, 9, 18 and 30 months. Working cooperatively with the child's primary care provider, the PNP's assist in arranging referrals to health, social, or educational resources. The program is coordinated through a central office at the University of Iowa which is supported, in part, by a modest appropriation from the state legislature.

ISSUES/BARRIERS:

There has been much recent debate regarding the developmental assessment tools appropriate for screening, in particular, the Denver Developmental Screening Test (DDST). Its limitations not withstanding, we have found it to be useful for early detection of moderate to severe disability. Training in its use and interpretation of results are conducted strictly in accordance with the manual. Furthermore, as PNP's become sufficiently experienced to observe qualitative as well as quantitative function, the detection potential of the DDST is increased. For example, a child with spastic hemiplegia will likely pass the motor items at age level; however, asymmetric use of the upper extremities should be noted. Furthermore, the premature infant who barely passes items for adjusted age is often referred for more complete assessment. In a pilot project we reassessed enrollees at age five to determine whether those who failed early screenings indeed had serious problems requiring intervention and whether those who passed now manifested previously undetected developmental problems. Virtually all those who failed "enhanced" screening proved to have significant problems upon more comprehensive evaluation. Of those who passed early screenings, no cases of cerebral palsy or moderate to severe mental retardation were uncovered. However, about 20% of this group performed significantly below a matched comparison group on tests of verbal, perceptual-motor, and pre-academic skills, raising concerns about potential school failure. Importantly, we did not consider this 20% to be "false negatives" from earlier screening as we did not expect the DDST to detect low severity developmental dysfunction during the infancy-toddler period. Until a better alternative appears, we view the DDST to be an adequate developmental screening tool for moderate to severe cognitive and motor disability when used by well-trained individuals with sufficient skill to make qualitative observations. Its major weakness is that it is skilled-focused. Thus, when used by itself as the sole determinant of need, interactional behaviors, social-emotional function, and parenting are domains which may not be assessed though they are likely more important. At present, the PNPs'attention to these issues, is neither systematic nor consistent.

The effectiveness of the DDST weakens as the child grows older when language and more subtle cognitive abilities must be assessed. What is needed is a screening "package" which will address all relevant areas of function and be sensitive to emerging developmental abilities over time. When such a package is available, our program will adopt it readily we realize the limitations of our present approach.

Additional lessons learned in the development of the program have centered on data collection. Significant changes in the date collection form used by the Iowa High Risk Infant Follow-up Program have occurred. An early extensive form used at some centers in Iowa was discontinued as we found that much of the maternal and infant information was not collected consistently and was not used. A shorter form was constructed for use by regional nurses whose time is limited; the tertiary center form is currently being revised. It is important that the expected uses of data be considered when data forms are being developed. Data needed for "head counts" will likely be less extensive than that needed for research. Lengthy forms are neither practical for a functioning program nor do they yield reliable data. Furthermore, every attempt should be made to utilize already existing systems for data collection (e.g. birth certificates and metabolic screening forms) and to coordinate efforts so that duplication is avoided, everyone's information needs are met adequately, and confidentiality is protected.

Iowa High Risk Infant Follow-up Program and Public Law 99-457:

With the advent of Public Law 99-457 it is evident that the high risk follow-up program must expand to serve infants whose risk status falls outside the traditional biological arena or does not become manifest until after discharge from the hospital. Program participants comprise a minority of the clients served in Iowa's statewide early intervention network. Some variation of the present model may be used in this expanded effort; more likely, the follow-up program will become one part of a larger early detection, referral, and support system.

From the five-year-old pilot testing program mentioned previously, we learned that surveillance for developmental concerns must continue, at least, to school entry age. Although it is logical for the health care system to take the lead in providing screening services for children at biological risk during infancy since there are typically unresolved health issues, we found no health problems in the cohort at age five which had not been previously detected. It seems reasonable that the responsibility for monitoring should gradually shift to the educational system as the child grows older. In Iowa, we would like to develop a mechanism for making this transition. It can be argued that surveillance for low severity problems (i.e. learning disabilities) should take place between 30 months and 5 years. We agree; however, at present there are few public programs which address low severity problems from a preventive point of view. Eligibility requirements are such that only children with more severe difficulties qualify for publicly-funded early intervention/preschool programs. With renewed attention to young children at the state and federal level, new programs to address these needs will likely appear.

The Iowa High-risk Infant Follow-up Program is a cooperative program of

Department of Pediatrics
The University of Iowa
Iowa City

Iowa Mobile and Regional Child Health
Specialty Clinics
The University of Iowa
Iowa City

Iowa Methodist Medical Center
Des Moines

St. Luke's Hospital
Cedar Rapids

UNIVERSITY OF IOWA HOSPITALS AND CLINICS

FOUNDED 1847

The Iowa High-risk Infant Follow-up Program

IOWA HIGH RISK INFANT FOLLOWUP PROGRAM
FORM 4

Rev. 12/85; Effective: Births 1/86

BASELINE DATA

GENERAL CODING INSTRUCTIONS

Every item whose code is to be entered in a box must be coded on every form. NO BLANK BOXES.

Any coding areas designated by lines relate to the preceding box coded item and may be left blank only if that preceding item code meets the specified criteria for skipping.

Code for unknown (missing data): Unless otherwise specified, code a ⑨ in each blank for that item.

Code for "not applicable": Unless otherwise specified, code an ⑧ in each blank for that item.

---

columns

Form Number, Card Number [4] [01] (1- 3)

A IDENTIFYING DATA:

Followup Number: ☐☐☐☐☐☐ (4- 9)

(First 2 digits of followup # represent the site identifying the child as eligible for the followup program. If any NICU care is given at University of Iowa Hospitals, the child is assigned a U of I number; baseline data form is then completed by Iowa City PNP's).

01 = University of Iowa Hospitals, Iowa City
02 = St. Luke's Methodist, Cedar Rapids
03 = Iowa Methodist Medical Center, Des Moines
04 = Sioux City, CHSC
05 = Ottumwa, CHSC
06 = Mason City, CHSC
07 = Davenport, CHSC
08 = Waterloo, CHSC
09 = Carroll, CHSC
12 = Ft. Dodge, CHSC
13 = Spencer, CHSC
14 = Dubuque, CHSC
15 = Burlington, CHSC
16 = Council Bluffs, CHSC

Enrollment Type:
1 = High Risk Infant Followup Program (identified during initial hospitalization)
2 = High Risk Infant Followup Program & Communication Screening
3 = High Risk Infant Followup Program (D/C normal - illness in first 28 days of life ☐ (11)

Child's Name: ☐☐☐☐☐☐☐☐☐☐☐ last , ☐☐☐☐☐☐☐☐ first (13-31)

Parent's (or Guardian's) Name: ____________ last ____________ first

Address: ____________ street ____________ city

____________ county ____________ state ____________ zip code

Telephone: ( ) - ____________ area number

Local Physician ____________

____

Birthdate: (mo, day, yr)	☐☐☐☐☐☐	(33-38)
Sex: 1=male 2=female 3=undifferentiated	☐	(40)
Child's hospital no.: (Begin number in column 42)	(42) ☐☐☐☐☐☐☐☐☐☐	(42-51)
Transferred: 1=No, inborn 2=Yes	☐	(53)
Enrollment criteria met: Code 1=No 2=Yes		
Birthweight < 1500 grams:	☐	(55)
RDS: (documented diagnosis in chart, differentiated from other signs of respiratory distress, must have had assisted ventilation and/or CPAP $\geq$ 2 hours)	☐	(57)
Clinical diagnosis of CNS infection:	☐	(59)
Asphyxia neonatorum: (5 minute apgar $\leq$ 6)	☐	(61)
Hypoglycemia: (two consecutive blood glucose levels $\leq$ 40 mgm%)	☐	(63)
Seizures: (documented in physicians' progress notes with concurrence of neonatologist (Level III) or attending pediatrician (Level II)	☐	(65)
Hypotonia: (documented in chart at time of discharge)	☐	(67)
Polycythemia (central crit $\geq$ 65 and/or peripheral crit $\geq$ 70 occurring within the first 24 hours of life)	☐	(68)
Ventilatory assistance $\geq$ two hours:	☐	(69)
Other reason (primary) for enrollment: (code "no" unless none of nine criteria listed above are met)	☐	(71)

1=No
2=Hyperbilirubinemia: requiring exchange transfusion
3=SGA
4=Sepsis (Positive blood and/or CSF Cultures)
5=IVH
6=Sib meets criteria
7=Psychosocial conerns
8=Other, specify ______________________________

Current status in High Risk Program:	☐☐	(73-74)

01=Active
02=Lost to followup - no screening exams
03=Direct referral to local program (e.g., AEA) - no screening exams
04=Direct referral to University Hospital School - no screening exams

Screening site (use enrollment center codes - p. 1)	☐☐	(75-76)
Infant's county of residence at time of birth: (Appendix A)	☐☐	(78-79)
Was this mother directed to a regional perinatal center (Level II or III hosp.) prior to delivery (following the identification of obstetrical risk factors): 1=NO 2=Yes	☐	(80)
Form Number, Card Number 41 02		(1- 3)
Repeats cols. 4-9 from Card 1		(4- 9)

B NEONATAL

Resuscitation at birth: (treatment within the first hour of life)
1=No 2=Yes, methods listed 3=Yes, other methods
(If "1" or "3" to to Col. 20) ☐ (11)

Type of treatment: 1=No 2=Yes

O_2 mask or in oxyhood - no positive pressure used: ___ (12)

O_2 bag and mask, positive pressure used: ___ (13)

Intubation - ETT with bagging, assume with O_2: ___ (14)

Narcan: ___ (15)

Volume expander: ___ (16)

$NaHCO_3$/THAM: ___ (17)

Other drugs: 1=No 2=Epinephrine 3=Other ___ (18)

Birthweight: (use nursery weight - grams) ☐☐☐☐ (20-23)

Length: (within first 3 days of life - cm) ☐☐.☐ (25-27)

OFC: (within first 24 hours of life - cm) ☐☐.☐ (29-31)

Gestational age by exam: (Ballard - weeks) ☐☐ (33-34)

(To code: If infant asphyxiated use Ballard after 6-12 hours of age
if available
If range ≥ 2 weeks - code mean
If 2 consecutive weeks - code earlier GA
If more than 2 weeks discrepancy between physician's and nurse's assessment
(Level II), discuss with infant's pediatrician
If infant transferred to U of I < 5 days of age - use U of I gestational exam
If < 26 - code 26 - use this also in computing adjusted age for screening exams.)

Size compared to GA: (Colorado growth chart, GA by exam)
1=Average 2=Large 3=Small ☐ (36)

One minute Apgar: ☐☐ (38-39)

Five minute Apgar: ☐☐ (41-42)

Sepsis: 1=No 2=Suspected, ≥ 7 days antibiotics, cultures negative
3=Yes, proven by positive blood and/or CSF culture ☐ (44)

Necrotizing enterocolitis: 1=No 2=Suspected, treated or clinically
compatible but not proven 3=Yes, documented by surgery or x-ray evidence
of intramural air ☐ (46)

Apnea: 1=No 2=Yes, documented in physicians' progress notes or hospital's
apnea sheet 3=Yes, documented as in No. 2, other treatment
(If "1" or "3" - go to Col. 53) ☐ (48)

Type of treatment: 1=No 2=Yes

Stimulation/observation: ___ (49)

CPAP: ___ (50)

Respirator: ___ (51)

Theophylline/caffeine: ___ (52)

PDA: 1=No 2=Clinical evidence such as LA AO ratio increase, pulses full, increased heart size by x-ray, no treatment. 3=Clinical evidence present and medically treated 4=Documented by surgery and/or catheterization ☐ (53)

Head ultrasound: 1=No 2=Yes, results normal 3=Yes, results abnormal ☐ (55)

Head CT: 1=No 2=Yes, results normal 3=Yes, results abnormal ☐ (57)
(If ultrasound and CT are both coded 1 or 2 - go to Col. 65)

Type abnormal results: Code 1=No 2=Yes
Consistent with IVH ___ (58)

Enlarged ventricles: ___ (59)

Porencephalic cysts: ___ (60)

Consistent with ICH other than IVH: (e.g., subdural, subarachnoid, intraparenchymal thalamic, venous thrombosis and hemorrhage) ___ (61)

Other abnormal results: ___ (62)

Respiratory therapy: (Any respiratory assistance including the use of oxygen occurring anytime beyond the first hour of life. ☐ (65)
1=No 2=Yes 3=Yes, surgery only 4=Yes, hood only
(If "1", "3", or "4" go to Col. 68)

Ventilator: 1=No 2=Yes ___ (66)

CPAP: 1=No 2=Yes ___ (67)

Bronchopulmonary dysplasia/Chronic lung disease: 1=No 2=Yes ☐ (68)

Bilirubin drawn: 1=No 2=Yes ☐ (70)
(If "NO" - go to Card 3, Col. 11)

Maximum total bilirubin: (mg%) ___ ___.___ (71-73)

Phototherapy: 1=No 2=Yes ___ (74)

Form Number, Card Number 4 | 03 (1- 3)
Repeat cols. 4-9 from Card 1 (4- 9)

ICD codes for other significant neonatal disorders not recorded on this form: 1=No 2=Yes ☐ (11)
(If "No" - go to Col. 31. If "Yes" write in diagnoses; Central High Risk Office will code.)

________________________________ ___ ___ ___.___ ___ (13-17)

________________________________ ___ ___ ___.___ ___ (19-23)

________________________________ ___ ___ ___.___ ___ (25-29)

C SOCIOECONOMIC DATA; (Information valid at time of infant's birth)

Mother's age; (years) ☐☐ (31-32)

Father's age: (years) ☐☐ (34-35)

Mother's race: 1=Caucasian 2=Caucasian, Spanish surname 3=Black 4=Am. Indian 5=Oriental 6=S.E. Asian 7=Other. ☐ (37)

Father's race: 1=Caucasian 2=Caucasian, Spanish surname 3=Black 4=Am. Indian 5=Oriental 6=S.E. Asian 7=Other ☐ (39)

Mother's marital status: 1=Single 2=Engaged (includes cohabitation) 3=Married 4=Separated 5=Divorced 6=Widowed ☐ (41)

Mother's domicile: (1980 census) 1=Rural, Farm (< 2,499 population) 2=Non-farm (< 2,499 population) 3=Town (2,500-14,999) 4=City (15,000-49,999) 5=Urban (≥ 50,000) ☐ (43)

Codes for education type and level:

Type: 1=Regular
2=Resource (e.g., "mainstreamed", consistent LD classes but also participates in regular classrooms)
3=Self contained (separate classrooms within regular facility and/or institutionalization)

Level: Code the highest elementary or secondary grade completed plus one year for each year of college completed: (26-28 hours undergraduate level; 15-18 hours graduate level)

Guidelines: 01-12=elementary through high school
12=GED
13=Vocational, trade school completion
14=Associate of Arts Degree
15=RN, diploma
16=RN, BS
16=BS, BA
18=MA
20=Medical, dental, legal, veterinarian degree

Mother's education type: ☐ (45)

Mother's education level: ☐☐ (47-48)

Father's education type: ☐ (50)

Father's education level: ☐☐ (52-53)

D DISCHARGE DATA: Discharged To: ☐ (55)
1=Home/Biological Parents
2=Foster home
3=Level I nursery
4=Level II nursery
5=Other tertiary nursery - out of state
6=Other out-of-state nursery
7=Home/Adoptive Parents
8=Other level III nursery

Weight at discharge: (gm - within 3 days of discharge) ☐☐☐☐ (57-60)

Length at discharge: (cm - within 3 days of discharge) ☐☐.☐ (62-64)

OFC at discharge: (cm - within 3 days of discharge) ☐☐.☐ (66-68)

Total number of days hospitalized from birth: ☐☐☐ (70-72)

Discharged on any of the following life support/monitor systems: 1=No 2=Yes (If "1" - do not code following items) ☐ (74)

Oxygen: 1=No 2=Yes, without ventilatory support 3=Yes, with ventilatory support ___ (75)

Apnea Monitor: 1=No 2=Yes ___ (76)

Nutritional Support: 1= No
2= Gastrostomy
3= NG Tube
4= CVN
___ (77)

Tracheostomy 1= No 2= Yes ___ (78)

CHSC Information Only:

DISCHARGE MEDS______________________________

RLF CHECK______________________________

HEARING CHECK______________________________

NEONATAL SCREEN______________________________

IOWA HIGH RISK INFANT FOLLOW-UP PROGRAM
SCREENING EXAMINATION EFFECTIVE 7/88

FORM/EXAM NO 2 0 ☐

NAME ______________________

FOLLOW-UP NUMBER ☐ ☐ ☐ ☐ ☐ ☐

PNP ______________________

EXAM SITE ☐ ☐

AGE CALCULATION

DATE OF EXAMINATION ______________________ ☐ ☐ ☐ ☐ ☐ ☐

BIRTHDATE ______________________ ☐ ☐ ☐ ☐ ☐ ☐

CHRONOLOGICAL AGE ______________________ MONTHS, WEEKS ☐ ☐ ☐

ESTIMATED GESTATIONAL AGE ______________________ ☐ ☐

ADJUSTED AGE ______________________ ☐ ☐ ☐

INTERCURRENT HISTORY

MAJOR ILLNESSES ______________________ ☐

REHOSPITALIZATION ______________________ ☐

PSYCHOSOCIAL ______________________ ☐

SURGERY ______________________ ☐

OTHER ______________________ ☐

1=NO
2=YES
3=UNKNOWN

DDST

RESULTS OF EXAM ______________________ ☐

1=NORMAL
2=ABNORMAL
3=QUESTIONABLE
4=UNTESTABLE
5=NOT DONE

BODY MEASUREMENTS

WEIGHT (kg) ______________________ ☐ ☐ . ☐

WEIGHT (%) ______________________ ☐ ☐

LENGTH (cm) ______________________ ☐ ☐ ☐ . ☐

LENGTH (%) ______________________ ☐ ☐

OFC (cm) ______________________ ☐ ☐ . ☐

OFC (%) ______________________ ☐ ☐

PHYSICAL/NEUROLOGICAL

HEENT ______________________ ☐

PULMONARY ______________________ ☐

CARDIAC ______________________ ☐

GASTROINTESTINAL ______________________ ☐

GENITOURINARY ______________________ ☐

MUSCULOSKELETAL ______________________ ☐

OTHER ______________________ ☐

1=NORMAL
2=ABNORMAL
3=ABNORMAL, PREVIOUSLY NOTED
4=ABNORMAL, PHY/PARENT MONITOR
5=DEFERRED

NAME ______________________________ PAGE 2

PHYSICAL/NEUROLOGICAL (CONT)

VISION ______________________________ ☐

HEARING ______________________________ ☐

HYPOTONIA ______________________________ ☐

HYPERTONIA ______________________________ ☐

MUSCLE STRENGTH ______________________________ ☐

MOVEMENT PATTERNS ______________________________ ☐

MUSCLE/TENDON STRETCH (DTR'S) ______________________________ ☐

DEVELOPMENTAL REFLEXES ______________________________ ☐

1=NORMAL,NO
2=ABNORMAL/YES
3=ATYPICAL/SUSPECTED

REFERRALS

PRIMARY PHYSICIAN ______________________________ ☐

1=NO
2=YES, ACUTE
3=YES, HEALTH MAINTENANCE
4=YES, CHRONIC

SUBSPECIALITY CLINICS ______________________________ ☐

SOCIAL SERVICE ______________________________ ☐

PUBLIC HEALTH ______________________________ ☐

DEVELOPMENTAL REFERRAL ______________________________ ☐

HEARING REFERRAL ______________________________ ☐

INTERVENTION PROGRAMS ______________________________ ☐

OTHER ______________________________ ☐

HIGH RISK RECHECK ______________________________ ☐

1=NO
2=YES
3=ALREADY FOLLOWED
4=REFUSED BY PARENTS
5=REFUSED BY PRIMARY PHY

SUMMARY

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KANSAS

In 1985 the Governor's Subcommittee on Early Childhood Developmental Services established the Kansas Plan outlining services to infants, preschool children, and their families. One of the goals of the Kansas Plan is the establishment of an early identification, intervention, and tracking system.

Funding from the Bureau of Maternal and Child Health, Special Projects of Regional and National Significance (SPRANS) assisted with the development of a database regarding infants and young children with handicapping conditions or at risk for developmental delays.

While the goal of an ongoing tracking system is yet to be reached, Kansas has developed a knowledge and information base and has identified the direction of the next phase of this effort. During the initial phase a pilot study of the two Level III NICU nurseries in Kansas was designed to test a list of risk factors and to provide a follow-up system for infants who met the criteria. A data reporting system was in the process of development. Key lessons influencing the future direction were learned from this study: 1) interdisciplinary agreement is necessary to establish risk factors as acceptable; 2) maintenance of confidentiality of both identifiable and "at risk" infants is necessary in order to allow reporting to occur. Today, uniform criteria for risk status and handicapping conditions exist through the cooperative efforts of the Level III NICU nurseries and the State Perinatal Council.

The specific criteria are located on the Early Identification and Intervention Project Hospital Reporting Form, which is used by both Level III and Level II nurseries.

In 1987 mandatory reporting of infants and children with identifiable conditions including mental retardation, handicapping conditions or chronic illness was established. Primary physicians are responsible for obtaining parental permission and reporting these infants and children to the state. While this legislation supports the concept of early identification, its utility is limited. As no specific information regarding the child or family identity is collected, referral for services or additional evaluation is not possible.

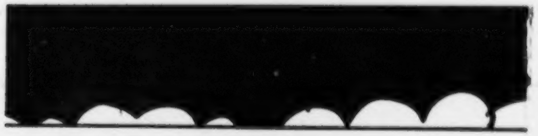
ISSUES/BARRIERS:

As Kansas develops its tracking system, the state will face many of the same challenges other states will encounter. Inadequate funding for follow-up health care and services represents a primary barrier to the implementation of a tracking system. In rural areas access to services is becoming a more serious problem. One of the greatest challenges identified is ensuring the cooperation of health care providers, hospital administrators, educators, and social service providers who will need to work collaboratively to serve the infants, toddlers and families of Kansas.

FUTURE PLANS:

In Kansas, the Early Identification and Intervention Project, the mandated reporting of birth defects and the efforts of the Kansas Interagency Coordinating Council are supporting the building of a framework for a comprehensive system of services for young children.

The tracking program is envisioned as an interagency, statewide system, to be funded by Special Education, Health and Social and Rehabilitative services. Collaborative efforts to develop an information/data system are being coordinated with the Kansas Division of Information and Systems Communication. This will be a priority for the Interagency Coordinating Council Cabinet Secretaries have agreed to meet and define requirements for Kansas as a beginning in moving toward this service.



WHO IS INVOLVED IN THE EARLY IDENTIFICATION AND INTERVENTION PROJECT?

The project has been developed by staff of the Crippled and Chronically Ill Children's Program, located in the Kansas Department of Health and Environment.

The project is also part of the Kansas Network for Young Children, known as "Make a Difference"; that involves staff of the Kansas Departments of Health and Environment, Education, Social and Rehabilitation Services, Administration, and the Kansas Board of Regents.

In addition to services offered regularly by these departments, the "Make a Difference" project supports a toll-free information line (1-800-332-6262) where **anyone** can obtain information on services offered throughout Kansas for children with handicaps and their families.

"Make a Difference" also supports four Regional Services Coordinators who work directly with physicians and families to overcome obstacles to the child's treatment and education.

The coordinators and the counties they serve are:

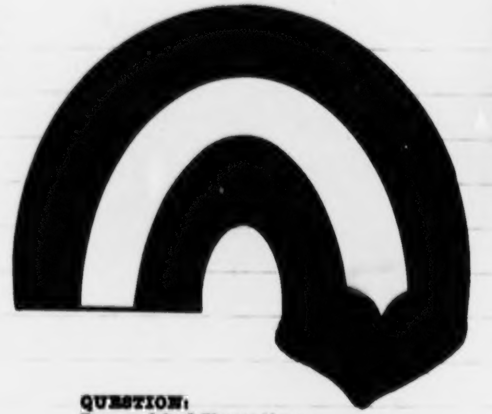
Michele Brungardt, Hays
St. Anthony's Hospital, Hays, Ks. 67601
1-800-332-6262
Serving: Ellis, Norton, Osborne, Phillips, Rooks, Russell, Smith

Sue Harris, Newton
Northview Development Center
14th and N. Duncan, Newton, Ks. 67114
1-800-332-6262
Serving: Harvey, Marion, McPherson, Sedgwick (excluding Wichita)

Sharon Hixson, Colby
Northwest Kansas Educational Service Center
210 S. Range, Suite 126, Colby, Ks. 67701
1-800-332-6262
Serving: Cheyenne, Decatur, Gove, Graham, Logan, Rawlins, Sheridan, Sherman, Thomas, Trego, Wallace

Nancie Linville, Deerfield
U.S.D. 216, Deerfield, Ks. 67838
1-800-332-6262
Serving: Clark, Finney, Ford, Grant, Gray, Greeley, Hamilton, Haskell, Hodgeman, Kearny, Lane, Meade, Morton, Ness, Scott, Seward, Stanton, Stevens, Wichita

**TOLL-FREE NUMBER
STATEWIDE FOR INFORMATION:
1-800-332-6262**



QUESTION:
True or false? The earlier a handicap is found and treated, the better the chances that it can be eliminated or reduced, and the lower the human and financial costs, both to those directly affected and to society as a whole.

ANSWER:
True, in most cases. A child who is likely to develop or has a handicapping condition can often be helped more effectively if the condition is discovered in the early years. The Early Identification and Intervention Project works closely with parents, the child's physician, school personnel, and others who care for the child to help locate services, financial assistance...any resources that can aid the child's development.

Anyone may call a toll-free number to obtain information on services, assistance and resources offered in Kansas for handicapped children and their families.

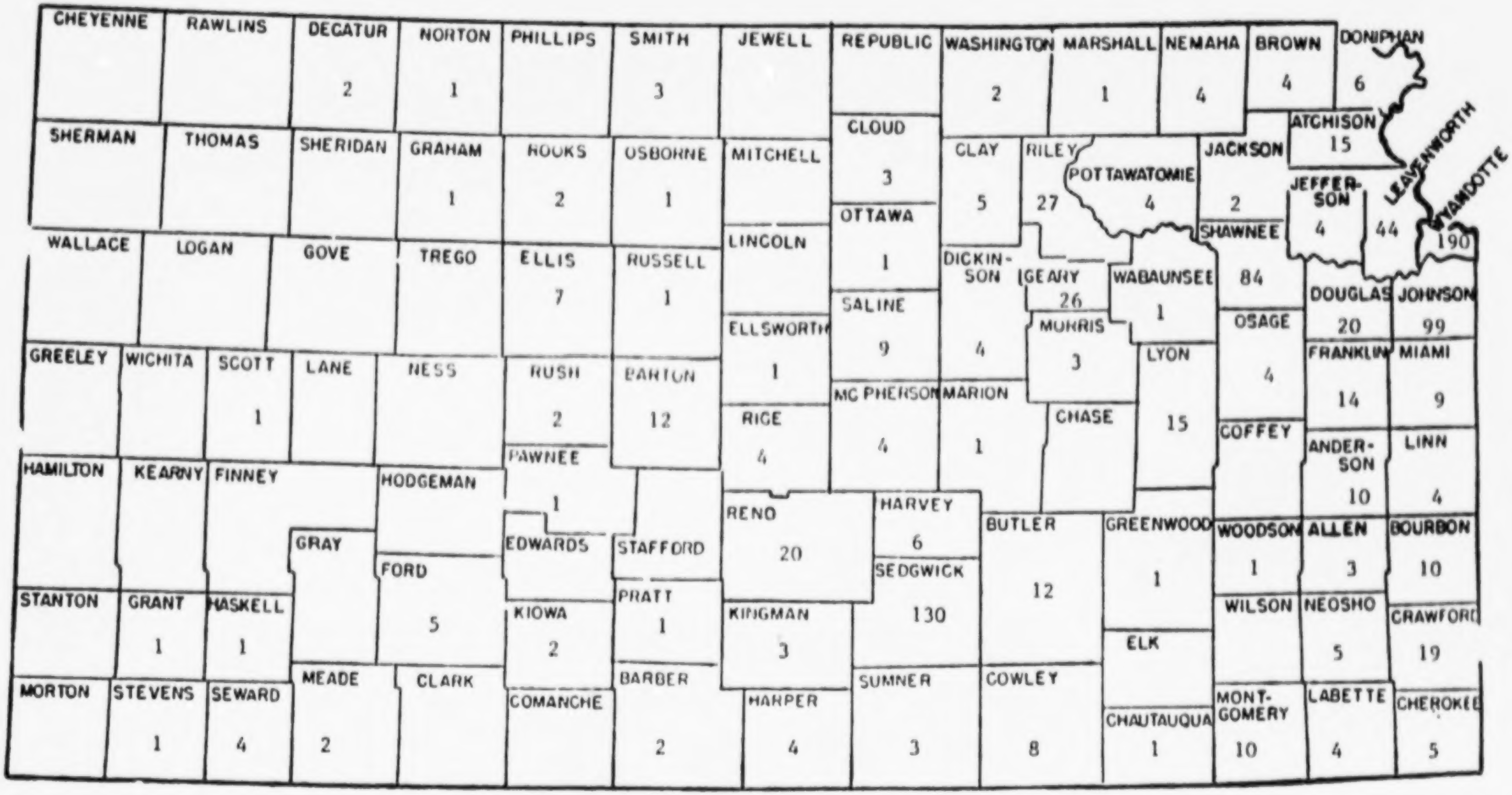
1-800-332-6262

EARLY IDENTIFICATION AND INTERVENTION PROJECT

...building
healthier
tomorrows

**A project of the
Crippled and
Chronically Ill
Children's
Program**

LEVEL III NICU DISCHARGES
1985 - 1988


CHEYENNE
RAWLINS
DECATUR 2
NORTON 1
PHILLIPS
SMITH 3
JEWELL
REPUBLIC
WASHINGTON 2
MARSHALL 1
NEMAHA 4
BROWN 4
DONIPHAN 6
SHERMAN
THOMAS
SHERIDAN
GRAHAM 1
ROOKS 2
OSBORNE 1
MITCHELL
CLOUD 3
CLAY 5
RILEY 27
POTTAWATOMIE 4
JACKSON 2
ATCHISON 15
JEFFERSON 4
LEAVENWORTH 44
WYANDOTTE 190
WALLACE
LOGAN
GOVE
TREGO
ELLIS 7
RUSSELL 1
LINCOLN
OTTAWA 1
DICKINSON 4
GEARY 26
WABAUNSEE 1
SHAWNEE 84
DOUGLAS 20
JOHNSON 99
GREELEY
WICHITA
SCOTT 1
LANE
NESS
RUSH 2
BARTON 12
ELLSWORTH 1
SALINE 9
MORRIS 3
LYON 15
OSAGE 4
FRANKLIN 14
MIAMI 9
HAMILTON
KEARNY
FINNEY
HODGEMAN
PAWNEE 1
RICE 4
MC PHERSON 4
MARION 1
CHASE
COFFEY
ANDERSON 10
LINN 4
GRAY
FORD 5
EDWARDS
STAFFORD
RENO 20
HARVEY 6
BUTLER 12
GREENWOOD 1
WOODSON 1
ALLEN 3
BOURBON 10
STANTON
GRANT 1
HASKELL 1
KIOWA 2
PRATT 1
KINGMAN 3
SEDGWICK 130
ELK
WILSON
NEOSHO 5
CRAWFORD 19
MORTON
STEVENS 1
SEWARD 4
MEADE 2
CLARK
COMANCHE
BARBER 2
HARPER 4
SUMNER 3
COWLEY 8
CHAUTAUQUA 1
MONTGOMERY 10
LABETTE 4
CHEROKEE 5

Attachment C

EARLY IDENTIFICATION AND INTERVENTION PROJECT
NEWBORN RISK FACTORS - DEFINITIONS
(1/19/88)

The risk factors defined below were developed by the staff of the Crippled and Chronically Ill Program, located in the Kansas Department of Health and Environment.

These definitions can be used to complete the Hospital Report form on handicapped infants which is sent to us upon discharge from NICU. Reports need to be completed only on infants who are handicapped or are at risk or developing a handicap.

1. _____ Five minute Apgar <7
2. _____ Auditory Impairment - Infant documented or perceived to be at risk based on factors such as:
    - family history or congenital hearing loss
    - prenatal intrauterine infection - toxoplasmosis, rubella, cytomegaloviris, herpes, syphilis
    - congenital malformations involving the head or neck
    - birthweight <1500 grams (approximately 3 lbs., 5 oz.)
    - hyperbilirubinemia at a level requiring exchange transfusion or maximum indirect bilirubin 18 mg% and over for full-terms, 15 mg% and over for preterms 34 - 38 weeks gestational age, and over 12 mg% for preterms <34 weeks gestational age
    - bacterial meningitis
    - severe asphyxia that is indicated by a five-minute Apgar ≤3 and failure to institute spontaneous respiration by ten minutes plus hypotonia persisting to two hours of age
3. _____ Apenea - Infant requiring monitoring after discharge for presumed problems in the control of breathing
4. _____ Birth weight <1500 grams
3. _____ Congenital anomalies - Defects that develop in utero and which result in a handicapping condition (see attached list for defects not included)
6. _____ Hyperbilirubinemia - requiring exchange transfusion or maximum indirect bilirubin 13 mg% and over for full-terms, 15 mg% and over for preterms 34 - 38 weeks gestational age, and over 12 mg% for preterms <34 weeks gestational age
7. _____ Hypertonia
8. _____ Hypoglycemis - blood glucose levels ≤30 mgm%
9. _____ Hypotonia
10. _____ CNS infection - documented bacterial meningitis or encephalitis
11. _____ Intracranial hemorrhage
12. _____ Prenatal intrauterine infection - toxoplasmosis, rubella, cytemegalovirus, herpes, syphilis
13. _____ Maternal age <15 >35
14. _____ Maternal multipara and age < 20
15. _____ Physician discretion
16. _____ Prematurity < 32 weeks
17. _____ Respiratory distress - CPAP or mechanical ventilation >6 hours
18. _____ Seizures
19. _____ Sepsis
20. _____ Small for gestational age - 5th percentile
21. _____ Large for gestational age - . 95tyh percentile
22. _____ Visual impairment - Infant documented or perceived to be at risk based on factors such as:

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- family history of ocular anomalies (congenital glaucoma, congenital cataracts, strabismus, severe refractive error)
- birth weight ≤1500 grams
- respiratory distress - CPAP or mechanical ventilation 6 hours
- intraventricular hemorrhage
- congenital malformations involving the head
- neonatal infections (documented sepsis, bacterial meningitis, encephalitis, toxoplasmosis, rubella, cytomegaloviris, herpes, syphilis)
- asphyxia that is indicated by a five-minute Apgar ≤3 and failure to institute spontaneous respiration by ten minutes plus hypotonia persisting to two hours of age
- bacterial meningitis
- albinism
- prenatal rubella or herpes

CONGENITAL ANOMALIES

Reportable congenital anomalies are defects that develop in utero and which may result in a handicapping condition. The following are not to be reported.

NORMAL VARIANTS: (Not to be included as malformations)

1. Pilonidal dimple
2. Tongue tie
3. Gum cysts
4. Hymenal tags
5. Diastasis recti
6. Umbilical hernias (completely covered with skin)
7. Natal teeth
8. Partial syndactyly (2nd and 3rd toes)
9. Vaginal and skin cysts
10. Esotropia
11. Flammeus nevi (port wine stain)
12. Hemangioma (less than 2 inches in diameter)

NOT DEFECTS:

1. Hemolytic disease
2. Torsion of spermatic cord and/or testes
3. Uretheral reflux (in absence of an associated anomaly)
4. Facial palsy
5. Erb's palsy
6. Rocker bottom feet
7. Chalsia

CONDITIONS WHICH MAY BE NORMAL VARIANTS OR SUBJECT TO VARIABILITY IN DIAGNOSIS:

1. Hydrocele
2. Single umbilical srtery
3. Tibial torsion

In accordance with K.A.R. 28-1-4, Congenital malformations in infants under one (1) year of age shall be reported by the administrator of all hospitals licensed in Kansas to the Kansas Department of Health and Environment.

CCICP

HOSPITAL REPORTING FORM
EARLY IDENTIFICATION AND INTERVENTION PROJECT

REPORTING HOSPITAL: ______________________________ **DATE:** ______________

Mother's county of residence at delivery:

____

Patient Transport:
Mother: Yes ______ NO ______
Infant: Yes ______ NO ______

Child's Initials: ____________________
First Middle Last

Birthdate: _____/_____/_____

Birth Order (Multiple Births)_____ Race______________ Male____ Female____

Date of Discharge _____/_____/_____ To______________________________
Home, Other Facility, Adoption, etc

NEWBORN RISK FACTORS:

_____Five minute Apgar <7
_____Auditory impairment
_____Apnea
_____Birthweight <1500 grams
_____Congenital anomalies
_____Hyperbilirubinemia
_____Hypertonia
_____Hypoglycemia
_____Hypotonia
_____CNS infection
_____Intracranial hemorrhage
_____Prenatal intrauterine infection
_____Maternal age <15 or >35
_____Maternal multipara and age <20
_____Physician discretion
_____Prematurity <32 weeks
_____Respiratory distress
_____Seizures
_____Sepsis
_____Small for gestational age
_____Large for gestational age
_____Visual impairment

DISCHARGE DIAGNOSIS:

____

____

PROBLEMS OF INFANT:

____

____

PRIMARY CARE PHYSICIAN: ______________________________

NOTE: Report only infants who have a handicap or are at risk for developing a handicapping condition.

Kansas Dept. of Health and Environment
Services for Children with Special Health Care Needs
900 SW Jackson
Landon State Office Building, 10th Floor
Topeka, Kansas 66612-1290
(913)

EARLY IDENTIFICATION AND INTERVENTION PROJECT
Kansas Department of Health and Environment
Topeka, Kansas 66620-0001
(913) 296-1318

REPORTING PHYSICIAN: ______________________________

CHILD'S CURRENT COUNTY OF RESIDENCE: ______________________________

CHILD'S IDENTIFICATION NUMBER:

Name: first, middle, last ______________________________

Birthdate: month, day, year ______________________________

Mother's county of residence at time of child's birth ______________________________

Sex ______________

Birth order of multiples or "1" if single ______________________________

Race ______________

DIAGNOSES (include ICD-9 numbers):

____

____

____

SERVICE OBJECTIVES/SERVICE PROVIDERS/TARGET DATES OF SERVICES:

____

____

____

I ______________________________ parent or guardian of
(Name)

______________________________ authorize the information
(Name)

on this form to be sent to the Early Identification and Intervention Project at the Kansas Department of Health and Environment, Topeka, Kansas. This information may be used only for research and statistical purposes and may not be used to identify my child.

____
Signature of Parent or Guardian

____
Witness' Signature

____
Date

MAINE

HISTORY:

Maine has an early intervention system involving 16 coordination sites, establishing state-wide opportunities for parents of infants and young children to access screening, evaluation and treatment. This includes assistance in the eventual transition to the public school. Interdepartmental coordination of services for infants and young children have been mandated through state legislation for the past 12 years. The 0-5 coordination system is managed on the state level by the Interdepartmental Coordinating Committee for Preschool Handicapped Children (ICCPHC). This committee is composed of representatives from three major state departments: Human Services, Educational and Cultural Services, and Mental Health and Mental Retardation; local agency and provider groups, parents, and advocacy organizations.

The 16 coordination sites were developed to ensure coordination and the availability of identification, referral, and transition services state-wide to all families. They are responsible for identifying service providers in their area, for oversight of the data management of area client activity on an interdepartmental basis, and for working with parents to find the best possible services for their children with special needs.

PURPOSE:

The overall goal of the data system is to provide a management tool for the interdepartmental service delivery system through the 16 coordination sites.

Data collection from the Interdepartmental Coordinating Committee for Preschool Handicapped Children perspective has been developing over the past five years with a tripartite focus:

1. To maximize local service provision through the use of technology for client record management, documentation and scheduling.

2. To secure the capacity for providing local, state and federal reports as needed without unnecessary additional paperwork at the local service level.

3. To establish the opportunity for longitudinal research and follow-through in the future, primarily focusing on the efficiency of Childfind, the effectiveness of the variety of forms of early intervention, impact of early intervention services upon school success after transition,etc.

Additionally, the environment of Maine's interdepartmental structure requires that the *definitions* of the *data* itself be *multidisciplinary*, and provide for the inclusion of children ages 0-5, including the prenatal referral period. The necessary protections and assurances for parents and children in the identification and service delivery process are of primary importance.

DESCRIPTION:

Maine uses one system to "track" services being provided to children and families—ranging from screening and evaluation services to early intervention services, including monitoring services should these be indicated. This system also includes the newborn screening activities at each of the participating birthing hospitals throughout the state.

Maine is beginning to use a common client identification number, assigned at the child's first entry into the early intervention system and remaining with the child through age five, or entry into the public school system. The six digit identification number maker electronic record transfer possible across coordination sites, facilitating rapid service planning and avoiding duplication of information gathering between providers and parents.

Benefits of the system are related not only to the immediate need to count children and services but also to long term analysis, including the ability to review the relationship between early intervention and later school success, or to analyze the relationship between the types of early intervention services provided, handicap or risk function, and the variety or range of outcomes as a result of intervention.

Maine utilizes an interdepartmental system for service provision, and must therefore utilize the same system for data collection and reporting purposes. The complex mix of disciplines, terminology, and existing reporting requirements within the participating agencies combines to create a challenge to complete, consistent and timely data entry. While interagency agreements are being negotiated and developed at the state level, individual sites are currently establishing interim protocols for data reporting that best respond to local practices and service delivery systems.

Two types of records are created for each child: master records and case records. The master record contains static information about the child such as name, address, insurance carrier, date of birth, and so on. Case records contain information about the particular services that a child needs. When the type of service has been identified, a case record is created detailing the service needs, frequency recommended, and provider and source of funding. A single client can have many case records. In addition to case records detailing services being provided, records are also entered detailing services that are recommended but unavailable, as well as services that are provided at a frequency less than that recommended. This information about children who are unserved or underserved can be used to guide resource development.

Every time a service is added, changed or completed another case record is created. If the child is being monitored, a master record is established, and a case record is created with the number of months to elapse before the needs should be reassessed. This is one attempt to avoid children "falling through the cracks" of the early intervention system.

There are 26 types of case records, with different types of data in each. A referral record, for example, contains information on who made the referral, whether the child was already screened or not, and if an evaluation was done prior to referral. A service record identifies the type of service, who paid for the service, how many units of service are provided each month, where the service is provided, and who provides it. There are also narrative records for information on the referral, screening or service. These narrative records allow for 60 characters of text. While this is not enough to enter the whole history, pertinent information can be entered.

Client data can be used by the staff of the local coordination site as an active management tool. It can help with staff scheduling, arranging and scheduling child team meetings, service tracking and monitoring either case management or case coordination duties. It can be helpful to the Site Coordinator in planning program development and determining areas of greatest need. Aggregated data can also give the state an accurate picture of the number of children with special needs receiving services or waiting for services. These data can be used to help produce the child count needed to meet federal requirements for Public Law 99-457.

BARRIERS/ISSUES:

Maine has made significant process towards the development of an interagency data management system designed to meet the needs of the local level coordination sites. Challenges remain in several areas.

Consistent reliable data input is an ongoing problem. As the system develops, changes in software are necessary, increasing the cost of the system, and presenting additional problems of keeping all system users up to date with changes.

The current system successfully addresses the requirements for state and federal reporting. Child counts and quarterly reports to identify where services are provided and where attention should be focused are generated from the data. However, maintaining local level interest and excitement about the data system is difficult when the "return" is seen as minimal.

The complexity of local needs, of the coordination process, and the variations of interpretations for terminology all demand an evaluation of our current system and practices.

Confidentiality and informed consent are critical issues for any data system or tracking program. Parents must clearly understand the relationship of their child's "file" and the electronic data base. In Maine, the application of the Family Education Rights and Privacy Act (FERPA) has been clearly articulated in relationship to early intervention and will soon be instituted in statute and regulations. Due to the interagency/interdepartmental nature of our service delivery system, it will be essential to develop comprehensive system policies and procedures to ensure the necessary safeguards and access for parents and providers. Interagency agreements must be developed that include provisions for data transfer, sharing and consistency. Discussions are now focusing on "common intake items" that could be established through the early intervention provider system, thereby ensuring that accurate and complete information is available.

FUTURE PLANS:

Maine's focus on technology during this current year demonstrates a commitment to utilize our experiences, findings, and feelings from the past four years in the refinement of our future technology activities in the implementation of Public Law 99-457. We are learning better how to ask the right questions, from the right people, and to take this knowledge to develop the "right fit" for Maine's data users. We will aggressively use our experiences from the past—good and not-so-good—in shaping the future of our system. Our basic tenet, though, will not likely change. We will use technology to improve the service delivery system and the quality of services for children and families, not simply to collect data. The final test of each data question will identify its relevance to the priority at hand: How does this help Maine to enhance and improve our interdepartmental/interagency service delivery system?

It is hoped that in the future the ICCPHC data system will be linked with other state data bases, as well as with records maintained on the state mainframe system Expansion of the capabilities of the system is envisioned to provide enhanced information regarding the frequency, periodicity, and payor for early intervention services, as well as to provide a system for tracking IFSP's. Future plans are being developed in light of the federal reporting requirements for participating in Public Law 99-457.

DATA INPUT FORM

Date __/__/__

Client ID Number: ______
Client Name: ____________________________
Case Manager: ____________________________
Address: ____________________________
____
Town: ____________________________

D.O.B. __/__/__
Handicapping Function __
Gender:M F

Primary Diagnosis: ____________________________________
Type of Placement: __
Related Services: __________________

Parent/Guardian: ____________________________
Address: ____________________________
____
____

Phone: (___) ___-____

Parent/Guardian 2 : ____________________________
Address: ____________________________
____
____

Phone: (___) ___-____

Insurance/Medicaid No.: ____________________________

Exit date: __/__/__

This form is for use with services, a different form for monitoring and screenings must be used.

SERVICES NEEDED

Client ID. ______
Date: __/__/__
Client Name: ____________________
Type of Service: ____________________________

For Whom: __ Client __ Parent(s) __ Sibling(s)
Served? __ Yes __ No
Why? ____________________________

Where: ____________________________
When: ____________________________
Who Pays: ____________________________

Screening

Client ID.: ______ Date: __/__/__
Client Name: ______________________________

Type of Screening:
__ Communication
__ Developmental
__ Genetic
__ Impedance Auditory
__ Orthopedic
__ Visual
__ Dental
__ Environmental
__ Hearing (Pure Tone)
__ Nutrition
__ Social/Emotional
__ Other Health Related
__ Comprehensive Screening (More than 2 of above)
__ Nursing Assessment (DPHN 0 - 2 visit)

Results:
__ Rescreen
__ Referral for Evaluation
__ No further services
__ OTHER

MARYLAND

Maryland generates a great deal of information related to individuals and programs. Most systems are based on specific program reporting requirements and reflect the information necessary for maintaining specific data collection. Due to these highly specialized informational needs, there is a lack of coordinated information available about Maryland infants who are handicapped or at-risk for developmental delay. The State is committed to developing an integrated tracking and data collection system which will ensure program continuity and the provision of appropriate services to every eligible child and family.

INFANTS AND TODDLERS PROGRAM (P.L. 99-457 PART H)

The Infants and Toddlers Program, Maryland State Department of Education and the Interagency Coordination Council for the implementation of P.L. 99-457 (Part H), define tracking as "a statewide system for gathering and maintaining demographic and at-risk data about infants and toddlers identified as at risk of developmental delay for the purpose of ensuring early and appropriate intervention as needed to foster their health and development."

PURPOSE:

The purpose is the early identification of the developmental problems of these children and linkage with existing services to meet their needs and the needs of their families. Secondly, it will provide important aggregate data for reporting and planning purposes to this population.

GOALS OF MARYLAND STATEWIDE TRACKING SYSTEM FOR INFANTS AND TODDLERS:

Overall Goal:

- To foster the health and development of infants and toddlers with handicaps or those who are at risk of developmental delay, and their families.

Related Goals are:

- To facilitate early identification of infants and toddlers with handicaps or at risk of developmental delay and their delivery of appropriate prevention and early intervention services.
- To assist their parents to have access to and contact with services available to meet their needs, primarily through the implementation of a tracking system and the case management model.

and

- to establish a statewide, interagency system of data collection for infants and toddlers in order to plan and improve services in a systematic way.

In 1988-89, the Tracking system is being piloted in five counties selected to demonstrate model systems of coordinated delivery of early intervention services to infants and toddlers. In addition, a statewide Central Directory of early intervention services and resources will be developed and implemented on a pilot basis.

The data collection system will compile data on the numbers of handicapped and at-risk infants and toddlers and their families in the state in need of early intervention services, the numbers of such infants and toddlers and their families served, the types of services provided, and other information as required. In addition, this system will maintain the data concerning the identified needs of handicapped infants and toddlers and their families that could be used by a case manager to track assessments, interagency delivery of services, and appropriate transition planning at age three. The Case Management component will be a significant part of this system. This approach demonstrates an integrated Tracking System, Central Directory, and Data Collection System.

The implementation of P.L. 99-457 in Maryland represents a new era in the provision of services for handicapped infants and toddlers. Prevention, early intervention, and a system of responsive, coordinated delivery of services to families are the cornerstones of these efforts. Early identification of potential difficulties and the use of early preventative services should ultimately reduce the need for more extensive and expensive services at a later date.

DESCRIPTION:

Maryland High Risk Infant Follow-Up Program
Maryland is one of the ten original States in the National Project Zero to Three. The early work of the Maryland High Risk Infant Follow-Up Program was outlined in the first addition of *Keeping Track.*

HISTORY:

In 1983 Maryland established a formal State Advisory Committee for review of the 0-3 population, issues and needs. The "Maryland Advisory Committee Project 0-3" took the lead for these activities under the aegis of the Preventive Medicine Administration, State Department of Health and Mental Hygiene. The Committee's goals and functions have now been assumed by the Governor's Interagency Coordinating Council on Infants and Toddlers (P.L. 99-457). In July, 1982, Misbah Khan, M.D., MPH., Associate Professor of Pediatrics, University of Maryland, was appointed as a consultant with specific responsibility to "develop and coordinate infant follow-up; determine long term effectiveness of neonatal regionalization; identify a practical assessment method for graduates of neonatal intensive care units (NICUs); and work with local health departments, community agencies and private child health providers to coordinate local support services for high risk neonates and their families."

The following year, July 1983, a grant-funded demonstration project was implemented in three select areas in the state of Maryland: Baltimore City, Baltimore County, and Washington County, representing urban, suburban and rural areas. The project was conducted by the University of Maryland's Department of Pediatrics in collaboration with the three local health departments, six Regional Intensive Care Nurseries and their respective institutions, the University of Maryland Department of Epidemiology and Preventative Medicine, the University of Maryland School of Nursing, and the Regional Center for Infants and Young Children of Maryland, Virginia and the District of Columbia. The goal of the Maryland High Risk Infant Follow-up Program was to demonstrate coordination and systematic follow-up of high risk infants, in their home communities, after discharge from Maryland Regional Intensive Care Nurseries. The aim was to ensure that all infants at risk and their families receive early and ongoing community health nursing case management and intervention, utilizing a coordinated network of community resources.

The principles and philosophy which were the foundation of the Maryland High Risk Infant Follow-Up continue to underlie the goals of the Maryland Department of Health and Mental Hygiene's efforts toward institutionalizing high risk infant follow-up and tracking:

1) The Health Department, at the state and local level, is a vital participant in interagency collaboration and ongoing services including systematic follow-up assessment, referral, data collection and reporting.

2) The community health nurse is the key professional with designated responsibility for family-oriented case management of infants and toddlers.

3) Staff training is a prerequisite which enables the community health nurse to acquire proficiency and confidence in the assessment of the child's growth, development and environment; in intervention, with referral as necessary; and in the utilization of local family-focused, interagency resources.

4) A comprehensive approach is critical to the care of high risk infants. This approach should include assessment at regular intervals of:

- the infant's growth, development and functioning
- parental competence
- parent/child interactions
- family functioning
- the home environment

5) The Maryland Department of Health and Mental Hygiene supports the right of every child to receive the full benefit of appropriate and timely services in order to attain optimal development and quality of life as the basic purpose of a tracking system. Nurturance of the infant demands an approach that is patient, caring, tender and individualized and yet provides high quality, specialized and technical care as needed. Parent and family support are essential elements of ongoing supervised care.

6) Accountability requires data collection concurrent with ongoing evaluation of the system.

The components of the Maryland High Risk Infant Follow-Up Program that have been integrated in local programs are:

1) A regionalized, continuing education program for community health nurses in assessment, intervention, referral, and case management, which is now funded by the private sector.

2) Follow-up procedures:

a. Obtain parental consent for follow-up

b. Identify infant

c. Notify local health department

d. Make initial home visit and home visit on infants referred for presenting risk factors.

3) Assessment of:

a) Infant's physical, cognitive, emotional neurological and social growth, development and functioning

b) Parental competence

c) Parent-child interaction

d) Family functioning

e) Home environment

A significant part of the Maryland program is the nature of its structure and collaboration between multiple institutions, agencies and local community service providers.

The interagency cooperation has continued beyond the original project. Every county in the state has a designated high risk community health nurse contact, with Baltimore City, Baltimore County and Prince George's County having formalized follow-up programs. Currently there is an ongoing effort to standardize community nursing plans of care, as well as follow-up policy and procedures. The Committee for Infant Follow-Up and Home Care, comprised of nurses and social workers from public and private agencies providing services to infants, toddlers and their families, continues to be an effective vehicle for enhancing interagency communication and cooperation.

The Department of Health and Mental Hygiene has maintained the commitment to the Neonatal Intensive Care Unit graduate, while expanding its scope to addressing the needs of the bio-psychosocial at-risk infant in a family-focused, community-based, framework with particular emphasis on preventative efforts.

FUTURE PLANS:

Collaborative efforts are currently underway to link specific statewide initiatives to provide tracking and data collection on s single point of entry, multi-agency basis. These initiatives are:

Public Law 99-457 System:
The proposed system includes tracking, data collection, and central directory in at least five locals in 88-89: Prince George's, Somerset, Baltimore City, Anne Arundel, Howard, Washington, Eastern Shore Consortium

Annie E. Casey Foundation Maryland Children and Family Services Reform Project
Maryland has received a five year $7.5 million seed grant to plan and implement a new interagency system of services to needy children and families. The system will focus on the preservation and self-sufficiency of families. Traditional categorical funding and delivery systems are being reviewed to determine improved practices that will promote the values of family independence and family preservation. A pilot program will allocate state funding resources and Casey funding resources in three zip code areas within Prince George's County. Results of these pilot efforts will determine the manner in which interagency cooperation is implemented at the state level and within other Maryland counties and Baltimore City.

Database for Preventable Childhood Disabilities:
The objective is to design and implement, through coordination of existing data systems and identification and filling of information gaps among such systems, a permanent comprehensive statewide data collection and analysis system for the purpose of planning and evaluating initiatives to prevent childhood disabilities. (Recommendation from Task Force on Prevention of Developmental Disabilities).

MASSACHUSETTS

The High Risk Infant Identification System (HRIIS) in Massachusetts is a legislatively mandated, statewide reporting system which identifies newborn infants who are considered to be at risk for neurological, physical, and developmental dysfunction. The HRIIS is a component of the High Risk Infant Program of the Department of Public Health, Bureau of Parent, Child and Adolescent Health (formerly the Division of Family Health Services). The overall mission of the High Risk Infant Program is to promote and strengthen the maternal child health care network in the Commonwealth through the early identification of high risk infants and facilitating their entry into the system of services.

PURPOSE:

The HRIIS promotes the mission of the High Risk Infant Program by providing a comprehensive data base with which to review and assess neonatal care, mortality, and morbidity. The information reported to the system provides an epidemiological picture of the prevalence of certain neonatal risk conditions, their geographic distribution and the types of services offered to families of these infants. Thus the goals of the High Risk Infant Identification System are to:

- Develop, refine, and maintain a comprehensive data system of new born infants reported to be at risk for developmental, neurological and physical dysfunction;
- Provide a tool for monitoring the neonatal transfer system, referral patterns and services available for high risk infants;
- Promote the early identification of infants at risk and their entry into the system of services which will support their optimum health and development.
- Provide a mechanism for complete and accurate reporting of birth defects

DESCRIPTION:

History of HRIIS

High risk infants are identified at birth and during the neonatal period through mandatory reports from maternity units and neonatal intensive care units (NICUs) in Massachusetts hospitals. A simple codable form was developed for the HRIIS which requests information reported by previous systems and adds other criteria to identify high risk infants and obtain follow-up information as well.

Thirteen criteria have been selected as identifiers of newborn infants who are at risk for neurological, physical, and developmental dysfunction. The specific criteria are listed on the High Risk Infant Identification Form.

The HRIIS form also includes descriptive information about the high risk infant, the infant's current status, transfer of the infant from one level of care to another and referral to the primary care provider and other services upon final discharge of the infant from the hospital. Thus the High Risk Infant Identification System is able to identify:

- Infants who are at risk for developmental, neurological and physical dysfunction;
- patterns of infant transfer and referral in order to assist in planning for regional services on behalf of high risk infants and families;
- infants at risk for hearing impairment in order to ensure that all such infants have an opportunity to register with the MDPH Hearing Evaluation Program for Infants and Toddlers;
- Newborn infants with birth defects in order to determine the baseline prevalence of congenital anomalies in Massachusetts.

FUTURE PLANS:

HRIIS and Public Law 99-457

The Massachusetts Department of Public Health, which is responsible for the development of early intervention services for infants and toddlers, is in the process of planning for the third year of implementation of Public Law 99-457. The HRIIS has been identified as a potential "child find" mechanism to identify newborn infants at-risk for developmental delay. To date, the HRIIS has been used as a data base for the development of a congenital anomaly surveillance system, as a casefinding tool for the Hearing Evaluation Program and for the production of statistical reports. The role of the system as a means of tracking individual infants and facilitating their referral into needed services is consistent with the goal of promoting optimum health and development of at-risk infants. It will mean expansion of the current system of providing data about identified infants to a system monitoring these infants and linking them to a specific service provider. Issues regarding the availability of resources, eligibility for services, the role of early intervention and primary care providers and the role of families in tracking infants will need to be addressed. The HRIIS provides a valuable source of information about at-risk infants and offers many possibilities for enriching the service system for infants and their families in the Commonwealth of Massachusetts.

For further information about the Massachusetts High Risk Infant Identification System contact the High Risk Infant Program directly. Available materials include the 1985 Annual Report, a training manual for completing the reporting form, a description of the Hearing Evaluation Program for Infants and Toddlers and program brochures.

HIGH RISK INFANT IDENTIFICATION
Confidential Information

THIS FORM MUST BE COMPLETED AT THE TIME OF TRANSFER, DISCHARGE OR DEATH FOR ALL INFANTS WHO MEET ONE OR MORE OF THE CRITERIA LISTED BELOW DURING THEIR HOSPITALIZATION. SEE LAST PAGE FOR INSTRUCTIONS TO FILL OUT THE FORM.

COMPLETED REPORTS ARE TO BE SENT TO:
DEPARTMENT OF PUBLIC HEALTH
HIGH RISK INFANT IDENTIFICATION SYSTEM
150 TREMONT STREET, 2ND FLOOR
BOSTON, MA 02111

INFANT

1. Name of infant ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐ (Last) ☐☐☐☐☐☐☐☐☐☐☐☐ (First)
2. Date of birth ☐☐/☐☐/☐☐
3. Birthweight ☐☐ lbs. ☐☐ ozs. OR grams ☐☐☐☐
4. Gestational age in weeks ☐☐
5. Sex Male ___ Female ___ ☐
6. Hospital of birth ______________________________ ☐☐☐☐

MOTHER

7. Name of mother ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐ (Last) ☐☐☐☐☐☐☐☐☐☐☐☐ (First)
8. Home address ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐ (#, street, apt.)
☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐ (City/Town) ☐☐☐☐☐ (Zipcode) ☐☐☐
9. Source of payment for infant's bills: Parent(s) ___ Medicaid ___ BC/BS ___ Other ______________ ☐

CRITERIA FOR IDENTIFICATION OF HIGH RISK INFANTS

10.
- ☐ Birthweight less than or equal to 2500 grams (5 lbs. 8 ozs.)
- ☐ Birthweight less than 10th percentile for gestational age (SGA)
- ☐ More than 48 hours in NICU; reason: ______________ ☐☐☐
- ☐ APGAR score of 5 or less at 5 minutes ☐☐☐
- ☐ Mechanical ventilation (intubation) for 24 hours or more
- ☐ Seizure(s)
- ☐ Intracranial hemorrhage
- ☐ Neurologic abnormality (palsy, abnormal tone, etc.): ______________ ☐☐
- ☐ Exchange blood transfusion for hyperbilirubinemia
- ☐ Congenital or perinatal infection: (specify) Rubella ___ Toxoplasmosis ___ Cytomegalovirus ___ Herpes ___ Syphilis ___ Meningitis ___ Other ______________ ☐☐☐
- ☐ Congenital anomaly(ies), describe: ______________ ☐☐☐☐☐☐ ☐☐☐☐☐☐ ☐☐☐☐☐☐
- ☐ Mother who had an active infection during pregnancy: (specify) Rubella ___ Toxoplasmosis ___ Cytomegalovirus ___ Genital Herpes ___
- ☐ Family member (blood relative) who has had a hearing loss since childhood ☐

11. Date of discharge or transfer from BIRTH HOSPITAL ☐☐/☐☐/☐☐ Medical Record# ☐☐☐☐☐☐☐☐

DISCHARGE AND TRANSFER

12. Transferred to NICU or other ICU? No ___ Yes ___ ☐
Name of NICU/ICU ______________________________ ☐☐☐☐
Date of discharge or transfer from NICU/ICU ☐☐/☐☐/☐☐ Medical Record# ☐☐☐☐☐☐☐☐
13. Transferred from NICU/ICU to COMMUNITY HOSPITAL or NORMAL NURSERY? No ___ Yes ___ ☐
Name of COMMUNITY HOSPITAL or NORMAL NURSERY ______________________________ ☐☐☐☐
Date of discharge from Community Hospital/Normal Nursery ☐☐/☐☐/☐☐
Medical Record# ☐☐☐☐☐☐☐☐ ☐
14. Is infant living? No ___ Yes ___ ☐
15. At final hospital discharge, was infant sent home to parent(s)? No ___ Yes ___

FOLLOW UP

16. Source of primary pediatric care (name of MD or facility) ______________________________ ☐☐
17. Referrals: Community Nursing Agency (specify) ______________________________ ☐☐
Early Intervention Program (name) ______________________________ ☐☐
Other medical or social service referrals (specify) ______________________________ ☐☐ ☐☐
18. SIGNATURE OF PERSON COMPLETING FORM ______________________________

Mass. DPH
Revised 7/87

copy 1: to be completed by hospital of birth

FORM # 185601

Instructions for completing the High Risk Infant Identification Form

I. The HRII form consists of 3 identical, carboned pages to be completed by:

1. Hospital of birth (PINK copy)
2. NICU (GREEN copy)
3. Community Hospital (BLUE copy)

II. Form flow

1. Hospital of Birth will:
   a. Initiate the form
   b. Send the completed 3 page form to the Department of Public Health at the time of infant's discharge home or death
   OR
   Send the completed PINK copy to the Department of Public Health and forward the remaining copies **with the infant's chart** to NICU at the time of infant's transfer to NICU.
2. NICU will:
   a. Update the form with any new or changed information
   b. Send the completed 2 page form to the Department of Public Health at the time of infant's discharge home or death
   OR
   Send the completed GREEN copy to the Department of Public Health and forward the remaining blue copy **with the infant's chart** to the community hospital at the time of infant's transfer to the community hospital.
3 Community hospital will:
   a. Update the form with any new or changed information
   b. Send the BLUE copy to the Department of Public Health at the time of infant's discharge home or death.

III. Specific instructions for filling out the form. (PLEASE DO NOT WRITE IN THE SHADED BOXES.)

Item 1:
Name of Infant
Write the infant's last and first names in the boxes indicated.

Item 2:
Date of Birth
Fill in the month, day and year. Place a zero in front of single months or days. Example 07/01/87.

Item 3:
Birthweight
Enter either pounds and ounces or grams. Place a zero in front of single digit pounds and ounces and three digit gram weights. Example 05 lbs. 01 ozs., 0950 grams

Item 4:
Gestational Age in Weeks
Enter the gestational age in weeks.

Item 5:
Sex
Place an 'X' in the space for male or female.

Item 6:
Hospital of Birth
Write the full name of the hospital of birth. Record out of hospital births as "at home," "birth center" or "en route."

Item 7:
Name of Mother
Write the birth mother's last and first names in the boxes indicated.

Item 8:
Home Address
Write the birth mother's complete home address in the boxes indicated.

Item 9:
Source of Payment for Infant's Bills
Place an 'X' in the appropriate space to indicate how the infant's hospitalization costs will be paid.

Item 10:
Criteria for Identification of High Risk Infants
Place an 'X' in the box(es) for each applicable criterion. ADDITIONAL CRITERIA SHOULD BE CHECKED AS THEY BECOME APPARENT.

More than 48 hours in NICU; reason — if no other criterion is checked, please write why infant was admitted to NICU.

Neurologic abnormality — write the type and location of the abnormality.

Congenital anomalies — please describe all abnormalities (conditions, syndromes) noted. Conditions listed in the International Classification of Diseases, 9th Revision, Chapter 14 (and others), are reportable.

Item 11:
Date of Discharge or Transfer from BIRTH HOSPITAL
Enter the date of discharge or transfer. Enter the INFANT'S medical record number, beginning in the first box and deleting all spaces, hyphens, etc.

Item 12:
Transferred to NICU or Other ICU?
Place an 'X' in the appropriate space. Write the name(s) of the NICU(s) where the infant was transferred. Enter the date of discharge from the final NICU.
Enter the INFANT'S medical record number, beginning in the first box and deleting all spaces, hyphens, etc.

Item 13:
Transferred from NICU/ICU to COMMUNITY HOSPITAL or NORMAL NURSERY?
Place an 'X' in the appropriate space. Write the name of the Community Hospital or Normal Nursery where the infant was transferred. Enter the date of discharge. Enter the INFANT'S medical record number, beginning in the first box and deleting all spaces, hyphens, etc.

Item 14:
Is Infant Living?
Place an 'X' in the appropriate space to indicate the infant's status at the end of all hospital care.

Item 15:
At Final Hospital Discharge, Was Infant Sent Home to Parent(s)?
Place an 'X' in the appropriate space. Please complete this question only at the end of the infant's entire hospital stay.

Item 16:
Source of Primary Pediatric Care
Write the name of the infant's physician or the name of the facility where pediatric care will be delivered.

Item 17:
Referrals
On the appropriate line, write the name of the agency to which a referral was made.

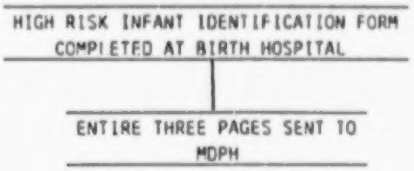
Item 18:
Signature of Person Completing Form
Write the full name of the person completing the form.

MASSACHUSETTS

FLOW CHART OF REPORTING PROCESS

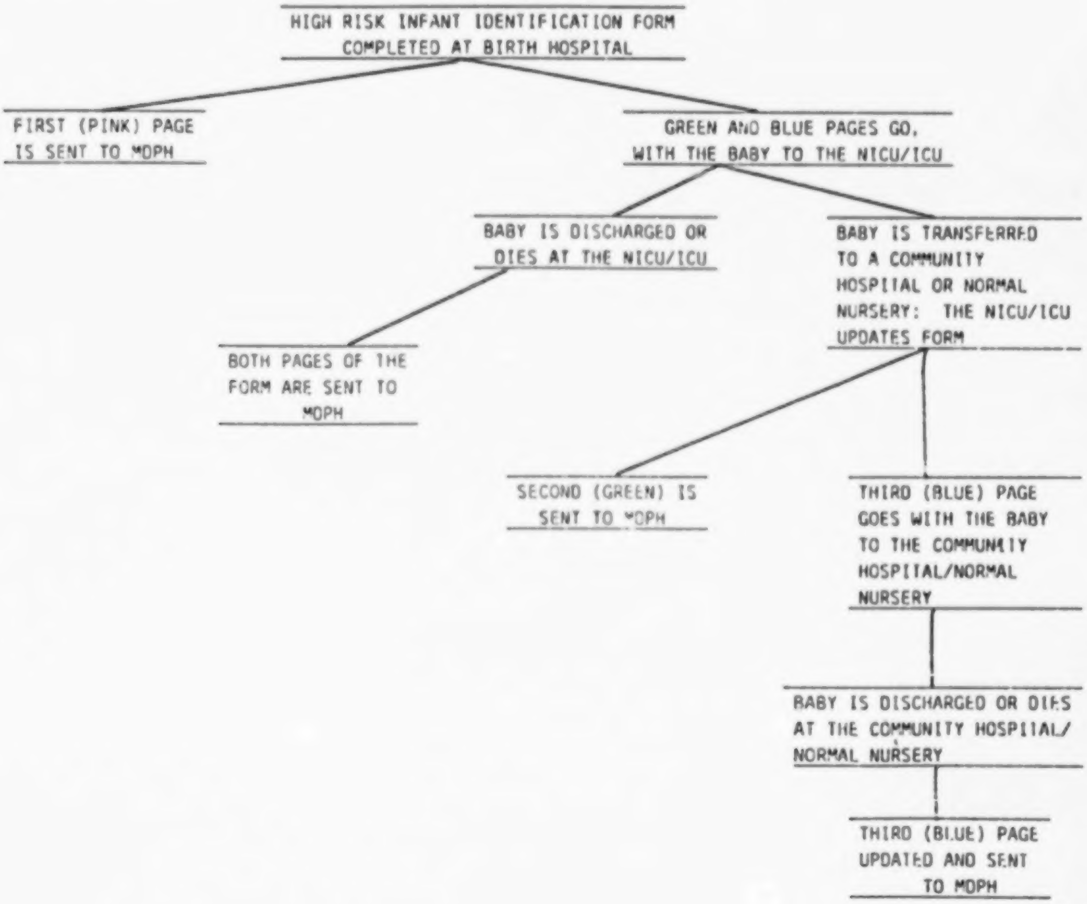
Example A:

INFANT IS IDENTIFIED AS HIGH RISK AND IS DISCHARGED FROM THE BIRTH HOSPITAL TO THE PARENT OR GUARDIAN.


HIGH RISK INFANT IDENTIFICATION FORM COMPLETED AT BIRTH HOSPITAL
ENTIRE THREE PAGES SENT TO MDPH

Example B:

INFANT IDENTIFIED AS HIGH RISK AND IS TRANSFERRED TO ANOTHER HOSPITAL OR NEWBORN UNIT


HIGH RISK INFANT IDENTIFICATION FORM COMPLETED AT BIRTH HOSPITAL
FIRST (PINK) PAGE IS SENT TO MDPH
GREEN AND BLUE PAGES GO, WITH THE BABY TO THE NICU/ICU
BABY IS DISCHARGED OR DIES AT THE NICU/ICU
BABY IS TRANSFERRED TO A COMMUNITY HOSPITAL OR NORMAL NURSERY: THE NICU/ICU UPDATES FORM
BOTH PAGES OF THE FORM ARE SENT TO MDPH
SECOND (GREEN) IS SENT TO MDPH
THIRD (BLUE) PAGE GOES WITH THE BABY TO THE COMMUNITY HOSPITAL/NORMAL NURSERY
BABY IS DISCHARGED OR DIES AT THE COMMUNITY HOSPITAL/ NORMAL NURSERY
THIRD (BLUE) PAGE UPDATED AND SENT TO MDPH

You have been given this pamphlet because your baby may need some special attention or services. In this pamphlet such babies are called "high-risk infants."

WHAT DOES "HIGH-RISK" MEAN?

High-risk infants are more likely than other infants to encounter health or developmental problems. *Many babies identified as high-risk at birth will be perfectly healthy and will not develop any problems.* All high-risk infants should be carefully watched to make sure they are developing to their fullest potential.

If problems do appear, special services during the first few years can make a great difference in your baby's future.

WHICH INFANTS ARE HIGH-RISK?

Infants considered high-risk are those for whom one or more of the following is true:

- weighed 5 lb. 8 oz. or less at birth;
- were born with a birth defect;
- had an APGAR score of 5 or less at 5 minutes after birth (based on heart and respiratory rate, color, muscle tone & reflexes);
- needed a respirator (breathing machine) for 24 hours or more after birth;
- had a seizure or convulsion;
- had bleeding in the brain;
- needed a blood transfusion because of severe jaundice;
- had major, ongoing problems with feeding or muscle tone;
- had an infection such as meningitis;
- whose mother had a virus such as rubella (German measles), toxoplasmosis, cytomegalovirus or genital herpes during pregnancy;
- have a blood relative with a hearing loss that began in childhood.

WHAT CAN YOU DO TO HELP YOUR HIGH-RISK BABY?

First, discuss your baby's risk factors with your doctor or other health care provider.

Then, if you're concerned about your baby's development or have questions about what services are available in your community, ask your health care provider or social worker for information or a referral.

WHAT CAN THIS PROGRAM DO FOR YOU AND YOUR BABY?

The Massachusetts Department of Public Health created the *High-Risk Infant Identification System* (HRIIS) to identify infants at high risk for health or developmental problems. All maternity hospitals in the state are required to report high-risk infants to the HRIIS. The program's goal is to identify all high-risk babies at birth and ensure that they receive the special care they need.

The HRIIS has a Perinatal Nurse Coordinator in each region of the state who can

- help you find services that offer special care, including programs sponsored by the Department of Public Health;
- give you information on what community health nursing and Early Intervention services are available in your area; and
- help you find resources for support such as health and social service organizations and parent groups.

High-risk babies with problems specific to hearing development are eligible for services offered by the Massachusetts Hearing Evaluation Program for Infants and Toddlers. If your baby is eligible for this program, you will be sent a letter telling you about these services. For more information, ask your hospital nurse for the blue Hearing Program brochure or call the regional Perinatal Nurse Coordinator listed on the back page of this pamphlet.

NEW JERSEY

The New Jersey High Risk Infant Follow-up Program, through the New Jersey Department of Health, Special Child Health Services, currently provides partial financial support through grants to the state's six designated perinatal/neonatal centers (9 sites) to track infants biologically at risk for developmental delay/disabilities.

PURPOSE:

The objectives of the New Jersey High Risk Infant Follow-up Program are designed to meet information needs related to program evaluation and service provision. Program objectives as described in the guidelines are as follows:

- —Enable early detection of developmental defects and handicapping conditions, and referrals for appropriate services for children so affected.
- —Evaluate effects of speciic forms of therapy and management during the perinatal period.
- —Assessment of currently recognized birth defects and handicapping conditions, and other such conditions which may be described in the future.
- —Analysis of outcome data for specific groups of infants selected on the basis of diagnosis and/or risk factors (i.e. birth weight, gestational age, asphyxia, respiratory distress syndrome, etc.).
- —Provision of parental education, emotional support and social services to families of high risk infants.
- —Increase the awareness of the health care community of developmental problems through provision of educational opportunities, and support of early evaluation, intervention and treatment.

Services are available on a sliding fee scale basis; third party and Medicaid reimbursement is sought in all programs.

In 1987 each center assessed an average of 119 infants per quarter. There were a total of 5,020 visits per year.

DESCRIPTION

Infants receiving care at a designated perinatal/neonatal care facility and meeting at least one of the nine criteria are eligible for the tracking program. The specific criteria are listed on the identification form.

Guidelines have been developed in New Jersey, by representatives of the designated perinatal/neonatal centers, which include general requirements for services, a common assessment protocol, and baseline data set (see Addendum A).

Follow-up services consist of a series of six visits scheduled for examination for evidence of developmental or physical problems: pre-discharge, 3, 6, 12, 24 months (corrected chronologic age) 4-5 years and 7-8 years (chronologic age).

ISSUES/BARRIERS:

High risk infant follow-up services have been supported in New Jersey by Special Child Health Services for almost a decade. Prior to this (1976) the Maternal and Child Health Program had funded neonatal follow-up as a Special Project of the Title V Program of Projects. As the number of programs have increased, several programmatic issues to be addressed have been identified.

A. Efficiency of the System

1. Other Resources

The High Risk Follow-up Program is to provide for early identification and referral of infants with developmental delays or other health problems.

In addition to the private practice sector in Ne Jersey, there is a network of services including child evaluation centers, case management services, and early intervention programs which are resources to which the HIgh Risk Follow-Up Program can refer. The Follow-Up Programs need to develop a cooperative system of referral for infants identified as needing comprehensive assessment and/or intervention.

2. Use of Personnel

All of the high risk follow-up programs utilize grant funds to support a full time pediatric nurse practitioner (PNP) who acts as program coordinator.

Several of the PNP's are involved in direct screening/assessment of infants. Most of the PNP's are in charge of scheduling and assist the neonatologist who performs the physical assessment of the infants. Service delivery models vary; most are one of the following:

a. arena assessment with the PNP, neonatologist, physical therapist and occupational therapist, and referral for specialty service,

b. physician assessment, referral for scheduled specialty clinics,

c. physical/developmental assessment completed by the PNP with availability of specialty consultation.

Service delivery models need to be examined to determine how appropriately and effectively staff are utilized.

B. Target Population

A major issue is that the infants coming to follow-up programs are not those infants of highest risk. Infants who do not receive ongoing primary care, but rather episodic acute care in emergency rooms are often suffering socio-economic risk as well as biological risk. These infants are frequently missed by the system because of inadequate tracking and outreach.

C. Data Collection

The individual data reporting forms originally developed for the programs (intake, pre-discharge, and quarterly reporting) have some ambiguous and duplicate items which have generated many questions and problems. Also the current system does not provide a way to track or maintain information submitted by primary care physicians or other service providers.

D. Attrition

Many of the programs have a high attrition rate. This may be attributed to :

— infants having normal testing results at 3, 6, and 12 months assessments (screenings)

— early diagnosis and referral for intervention

— on going assessments from attending primary care physicians who consider the follow-up programs a duplication of services.

E. Limited Numbers Served

Program eligibility is currently limited to "graduates" of the state's designated perinatal/neonatal centers (Level III). However, other special care nurseries (Level IIA & II) provide care to a significant number of infants meeting high risk criteria in New Jersey.

FUTURE PLANS:

Special Child Health Services will be undertaking a complete review of the High Risk Infant Follow-Up Program. The original task force will be reconvened to examine and make recommendations for revising the current system.

Goals and objectives will be revised.

The minimum criteria for follow-up will outline basic purposes for tracking and describe basic standards.

A system of tracking the socioeconomically at risk families will be developed.

A plan to reduce the attrition rate will be developed and implemented.

A protocol for discharge from active follow-up service and for coordinating follow-up with the primary care physician or other service providers will be incorporated in the criteria.

Reporting forms will be revised to consolidate and correct ambiguous data requests. This will simplify data entry and ensure the usefulness of the statistical information.

Integration of the Follow-Up Programs with the network of Early Intervention Programs, Child Evaluation Centers and primary care physicians will reduce duplication of services.

Special Child Health Services has been involved in interagency collaboration with the Departments of Education and Human Services for early intervention services since 1983. The application for Part H funds from the Department of Education, lead agency for P.L. 99-457, includes a proposal to provide the Department of Health - Special Child Health Services with Part H funds to support expansion of high risk follow-up services. Special Child Health Services is preparing to submit a proposal to the New Jersey Department of Education to expand high risk infant follow-up services to graduates of special care nurseries.

New Jersey State Department of Health
Special Child Health Services
CN 364
Trenton, New Jersey 08625-0364

High Risk Infant Follow-up Program

Hospital ID Number ______________

STATE USE ONLY

_ _ _ _ _ _ _ _ _ _ _

_ _ _ _ _

_ _ _ _ _ _ _ _ _ _

1. PROGRAM/FACILITY

Name: ____

Address: ______________________ (Number and Street) ______________________ (City) ________ (State) ________ (Zip Code)

2. BIRTH INFORMATION

a. Date of Birth: _ _/_ _/_ _ (mo day yr)　　b. Sex　[1] = Male　[2] = Female　[3] = Indeterminant

c. Race　[1] = White　[2] = Black　[8] = Other (Specify) ______________________ [9] = Unknown

d. Hospital/Place of Birth: ______________________ ______________________ (City) ____________ (State)

e. Residence at Birth: ____________ (City) ________ (State) ________ (County)　f. Current Residence: ____________ (City) ________ (State) ________ (County)

g. Measurements at Birth: _ _ _ _ grams　Length: _ _ _ _ cms　Head Circumference: _ _ _ _ cms

h. Plurality: [1] = Singleton　[2] = Twin　[3] = Other Multiple　[9] = Unknown　i. Gestation _ _ _ weeks　Corrected Age at Birth _ _ _ weeks

3. FAMILY INFORMATION

a. Mother: Date of Birth: _ _/_ _/_ _ (mo day yr) or Approximate Age, if unknown _ _ years　Highest Grade of School Completed _ _ years

b. Father: Date of Birth: _ _/_ _/_ _ (mo day yr) or Approximate Age, if unknown _ _ years　Highest Grade of School Completed _ _ years

c. Household Composition:　Number in the household _ _　Number of Siblings: _ _　Male(s): _ _　Female(s) _ _

d. Family Income:　[1] = $9,999 or less　[2] = $10,000 to $14,999　[3] = $15,000 to $19,999　[4] = $20,000 to $24,999　[5] = $25,000 to $29,999　[6] = $30,000 to $34,999　[7] = $35,000 to $39,999　[8] = $40,000 to $49,999　[9] = $50,000 or more

e. Primary Language in the Home:　[1] = English　[2] = Other, ______________________

f. Insurance Coverge　[1] = None　[2] = Medicaid　[3] = Blue Cross/Blue Shield Only　[4] = HMO Only　[9] = Unknown　[5] = Private, including multiple coverage　[6] = SCHS Sliding Fee Scale　[7] = 100% Self Pay

4. DISCHARGE INFORMATION

a. Date of Discharge: _ _/_ _/_ _ (mo day yr)　b. Discharged to:　[1] = Parents　[2] = Other Relative　[3] = Foster Care　[4] = Hospital ____________　[5] = Other ____________

c. Date CH-O Form sent to Special Child Health Services: _ _/_ _/_ _ (mo day yr)　If CH-O was updated, date of update: _ _/_ _/_ _ (mo day yr)

d. Measurements at Discharge:　Weight: _ _ _ _ grams　Length: _ _ _ _ cms　Head Circumference _ _ _ _ cms

e. Circle the status ("NO" or "YES") for each of the specific follow-up criteria below:

Birthweight (<1500 grams)	[1] = No	[2] = Yes	Complicated Sepsis/Meningitis	[1] = No	[2] = Yes
Perinatal Asphyxia	[1] = No	[2] = Yes	Hyperbilirubinemia	[1] = No	[2] = Yes
Assisted Ventilation	[1] = No	[2] = Yes	Intracranial Hemorrhage	[1] = No	[2] = Yes
Neonatal Seizure	[1] = No	[2] = Yes	Intrauterine Growth Retardation	[1] = No	[2] = Yes
Symptomatic Drug Withdrawal	[1] = No	[2] = Yes			

f. Diagnoses at Discharge:

1 ______________________
2 ______________________
3 ______________________
4 ______________________
5 ______________________
6 ______________________
7 ______________________
8 ______________________

STATE USE ONLY

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New York:

In the state of New York, the Department of Health is the lead agency for the implementation and maintenance of the Infant Health Assessment Program (IHAP), which began in 1983 with a Request for Application (RFA) directed to the 58 county/city health departments. Specifically directing the RFA to the health departments was determined as the best route for implementation because local health agencies already possessed many valuable components necessary to ensure the successful implementation of IHAP. The most valuable of these components was the worker, i.e. the public health nurse, (PHN), who knew the community, its needs and assets, and already had, or had the potential to have, credible links and liaisons with other health care and service providers. The program did not have to establish a new staff to learn the community and gain the credibility already belonging to the PHN, but rather could put its efforts into the actual tasks of identifying, tracking, assessing and linking these at-risk infants and children. With the exception of New York City, IHAP has been fully implemented across New York State.

PURPOSE:

The need for a coordinated, statewide identification and tracking system has become more evident during the four years of initial IHAP activities. New York State is ensuring the promotion of health and well being for the risk population of infants and toddlers. State efforts are continuing to promote provider awareness and cooperation with IHAP at both the local community and state levels. A major focus of IHAP is to ensure that the child is linked to and receiving appropriate services as indicated by assessed needs. In lieu of an actual provider the PHN, through IHAP, is the professional who is prepared to do the scheduled assessments at six months, one year and annually thereafter, and to administer the developmental screening tests at six months and three years.

DESCRIPTION:

The Infant Health Assessment Program uses the public health nurse as the key liaison. A second valuable component is the health departments' access to each county's vital records. Through this connection copies of birth certificates, which are made available to every health department, can be reviewed to identify infants who meet the IHAP eligibility criteria. These criteria are:

- maternal age less than 16 years
- gestational age less than 32 weeks
- birthweight less than 2001 gm.

Other IHAP eligibility criteria were

- inborn metabolic disorder
- major congenital anomaly
- 10 or more days stay in a neonatal intensive care unit (NICU)

In addition, the local health officer receives a report of positive results from the legally mandated newborn screening test which often leads to diagnosis of an inborn metabolic disorder. Frequently the local health officer receives notification of anomalies and lengthy hospital stays via referral liaisons with hospital and social services within the hospital.

Referral to the IHAP does not require parental consent to participate. Section 206.1J of the New York State Sanitary Code grants the Department of Health the right to data collection. If parents wish to discontinue their child's IHAP participation the case is closed upon request.

IHAP is a means of secondary prevention. The early identification of the at-risk child with subsequent linkage to service has helped to meet one of New York State's public health objectives of preventing or ameliorating the potential problems that could be resultant to the child's original at-risk status. Through all of these activities, coupled with the collection of relevant information, IHAP has established a valuable data base for review of incidence and prevalence of certain conditions. This data base has led New York to further consideration of exactly what criteria really constitutes at-(or high-) risk.

ISSUES/BARRIERS:

It is very important to New York State's IHAP to perfect, to the extent possible, the factors and indicators used to determine identification of risk status, as IHAP is envisioned as the foundation for the "child find" component for the implementation of P.L. 99-457.

In order to achieve this, the current eligibility criteria are currently being reviewed for possible modification. In addition to the need to clearly identify the most significant entry criteria, there is also a need to establish clear closure/exit criteria. A protocol for case closure from the tracking system was developed. However, the data reported by each county indicates that the protocol is not uniformly followed. For some counties there is a continued annual increase of enrollees without a balance of closures, while in other counties cases are opened and closed on an on going basis. This clearly indicates definite inequalities in implementation. IHAP needs to investigate further appropriate criteria for release from follow-up as well as determining criteria for ongoing follow up and monitoring.

FUTURE PLANS:

As the IHAP continues to grow, the collaborative efforts with New York State's implementation of PL 99-457 makes this an exciting time. The last few years of IHAP activities have been very timely and are supportive of making the implementation of PL 99-457 a reality in New York State.

Future efforts will be centered on further development of the open enrollment concept, permitting older infants and toddlers to enter the system, and further expansion into New York City.

IHAP is:

A statewide program to assure that your child will receive the help needed for the best growth and development in the early years.

Assistance, through early identification and referral to services in the community, to families of children, aged 0-5, who have special needs.

IHAP Eligibility:

- Infants born after a pregnancy of less than 32 weeks.
- Infants born weighing less than 2001 grams (about 4 lbs. 7 oz.).
- Infants who spend 10 days or more in a neonatal or special care unit.
- Infants born to mothers less than 16 years of age.
- Infants who have a diagnosed medical problem at birth or shortly thereafter - such as heart problems, respiratory problems or others.
- Infants and preschool children with other diagnosed special needs and/or potential developmental problems.

A Public Health Nurse Will:

- Contact you after your baby's birth.
- Explain IHAP to you.
- Offer support in your infant's care.
- Give you information about referrals, if they are needed, to services available in your community.
- Provide the reassurance of periodic assessment and screening tests. In this way you can have feedback on your baby's growth and developmental status. (See back page.)
- Contact you and/or your doctor periodically to follow your child's growth and development during the first years of life.

Parents:

- IHAP is a partnership with you. Its goal is the best possible outcome for your child.
- IHAP participation involves *no* cost to your family.

New York State Department of Health
BUREAU OF CHILD HEALTH

INFANT HEALTH ASSESSMENT PROGRAM: ASSESSMENT / FOLLOW-UP REPORT

Shaded areas must be completed for 6 month and 3 year report. Completion is otherwise optional.

A. IDENTIFYING INFORMATION CHILD'S NAME (last, first, middle initial)

DATE OF BIRTH M D Y | IHAP I.D. # | (If infant has not been previously registered in the program, please fill out the IHAP Registration Form.)

B. REPORTING PERIOD (check one only)

ASSESSMENT ☐ 6 MO 0   FOLLOW-UP ☐ 1 YR 1 ☐ 2 YR 2 ☐ 3 YR 3 ☐ 4 YR 4 ☐ 5 YR 5

C. THIRD PARTY PAYMENT RESOURCES (check all that apply)

☐ BLUE CROSS / BLUE SHIELD
☐ HEALTH MAINTENANCE ORGANIZATION
☐ OTHER HEALTH PLAN
☐ PHYS. HANDICAPPED CHILD. PROG.
☐ MEDICAID
☐ FAMILY COURT
☐ UNKNOWN
☐ NONE

D. PUBLIC ASSISTANCE (check all that apply)

☐ AID TO DEPENDENT CHILDREN
☐ HOME RELIEF
☐ WIC
☐ SUPPLEMENTAL SECURITY INCOME
☐ FOOD STAMPS
☐ OTHER (specify)

E. PRIMARY CARE PROVIDER NAME OF PHYSICIAN OR HEALTH FACILITY

STREET ADDRESS   TOWN, COUNTY

PROVIDER CATEGORY (check one only)

1 ☐ PEDIATRICIAN
2 ☐ GP / FP
3 ☐ INTERNIST
4 ☐ CLINIC
5 ☐ HEALTH CTR
6 ☐ OTHER

F. MEDICAL CONDITIONS

	OFFICE USE ONLY		OFFICE USE ONLY
1		4	
2		5	
3		6	

G. DEVELOPMENTAL STATUS (check one only in each category)

TEST USED

1 ☐ DENVER DEVELOPMENTAL
2 ☐ GESELL
3 ☐ MULTIPLE BATTERY
4 ☐ OTHER (specify)

ADMINISTERED BY

1 ☐ IHAP PROGRAM STAFF
2 ☐ DEVELOPMENTAL CENTER
3 ☐ PRIVATE M.D.
4 ☐ VISITING NURSE AGENCY
5 ☐ HOSPITAL/CLINIC/HMO
6 ☐ OTHER

TEST RESULTS ☐ NORMAL 1 ☐ SUSPECT 2 ☐ ABNORMAL 3

DATE ADMINISTERED M D Y

H. ANTHROPOMETRY

LENGTH / HEIGHT ______ inches or ______ CM   PERCENTILE ______
WEIGHT ______ lbs. ______ oz. or ______ grams   PERCENTILE ______
HEAD CIRCUM. ______ inches or ______ CM   PERCENTILE ______

GROWTH WITHIN NORMAL LIMITS ☐ YES 1 ☐ NO 2 IF NO: ☐ OVER 1 ☐ UNDER 2

DATE MEASUREMENTS TAKEN M D Y

I. FAMILY ENVIRONMENT (check all areas of deficiency which could place the child at risk developmentally)

☐ POOR ECONOMIC RESOURCES
☐ POOR SOCIAL SUPPORT
☐ INADEQUATE WELL CHILD CARE
☐ INADEQUATE HOUSING
☐ INADEQUATE NUTRITION
☐ OTHER DEFICIENCIES (specify)
☐ POOR PARENTING SKILLS

J. SPECIFIC REFERRALS MADE (each problem noted above should be reflected in a referral in the following section)

REFERRED BY CODES
1. IHAP NURSE
2. PRIMARY CARE PROVIDER
3. SPECIALIST
4. HOSPITAL/EMERGENCY ROOM
5. SOCIAL WORKER
6. DEVELOPMENTAL CENTER
7. SELF (FAMILY)
8. OTHER

STATUS CODES
1. UNDER CARE
2. COMPLETED CARE
3. STATUS UNKNOWN
4. NOT UNDER CARE

1 PROBLEM FOR WHICH FAMILY REFERRED ______ REFERRED BY ______ STATUS ______
REFERRED TO ______ (NAME OF PERSON / FACILITY / AGENCY) (SPECIALTY) (TOWN, COUNTY)

2 PROBLEM FOR WHICH FAMILY REFERRED ______ REFERRED BY ______ STATUS ______
REFERRED TO ______ (NAME OF PERSON / FACILITY / AGENCY) (SPECIALTY) (TOWN, COUNTY)

3 PROBLEM FOR WHICH FAMILY REFERRED ______ REFERRED BY ______ STATUS ______
REFERRED TO ______ (NAME OF PERSON / FACILITY / AGENCY) (SPECIALTY) (TOWN, COUNTY)

4 PROBLEM FOR WHICH FAMILY REFERRED ______ REFERRED BY ______ STATUS ______
REFERRED TO ______ (NAME OF PERSON / FACILITY / AGENCY) (SPECIALTY) (TOWN, COUNTY)

5 PROBLEM FOR WHICH FAMILY REFERRED ______ REFERRED BY ______ STATUS ______
REFERRED TO ______ (NAME OF PERSON / FACILITY / AGENCY) (SPECIALTY) (TOWN, COUNTY)

6 PROBLEM FOR WHICH FAMILY REFERRED ______ REFERRED BY ______ STATUS ______
REFERRED TO ______ (NAME OF PERSON / FACILITY / AGENCY) (SPECIALTY) (TOWN, COUNTY)

L. HOME VISITS (completed visits during period of report)

N. REPORT PREPARED BY   DATE PREPARED M D Y

TITLE   DATE RECEIVED AT REGIONAL OFFICE M D Y   DATE RECEIVED AT CENTRAL OFFICE M D Y

DOH59 (7/85)

77

Infant Health Assessment Program Registration Form

NYS Department of Health
Bureau of Maternal and Child Health

1. INFANT'S NAME: ______________________________
LAST FIRST MI

SEX ___ DOB __/__/__ APPROX GEST AGE: ___ WEEKS

2. PLACE OF BIRTH

______________________ COUNTY ______________ STATE ________

3. INFANT'S RESIDENCE:
STREET ________________ CITY (__) TOWN (__) VILLAGE (__) __________ CO __________ ZIP _____

MAILING ADDRESS (IF DIFFERENT FROM ABOVE):

____

4. MOTHER'S NAME:
______________________________ DOB __/__/__
LAST MAIDEN FIRST MI

5. METHOD OF INITIAL IDENTIFICATION

- **A** ☐ BIRTH CERTIFICATE REVIEW
- **B** ☐ HOSPITAL RECORD REVIEW
- **C** ☐ HOSPITAL REFERRAL
- **D** ☐ PHYSICIAN REFERRAL
- **E** ☐ NYS HEALTH DEPT. REFERRAL
- **F** ☐ OTHER: ______________ (SPECIFY)

DATE OF IDENTIFICATION __/__/__

6. REASON(S) FOR IHAP ENROLLMENT

- ☐ < 2000 GMS
- ☐ MOTHER'S AGE < 16
- ☐ < 32 WKS GEST.
- ☐ IMD: ______________ (SPECIFY)
- ☐ MAJOR CONG. ANOMALY: ______________ (SPECIFY)
- ☐ 10+ DAYS CARE IN PREM. NURSERY: ______________ (SPECIFY)

7. IF OTHER THAN IHAP CONDITIONS: PLEASE CHECK REASON AND SPECIFY RELEVANT DATA:

- ☐ BIRTHWEIGHT ______________
- ☐ PARENTING PROBLEMS ______________
- ☐ DRUGS/ALCOHOL ABUSE ______________
- ☐ MATERNAL AGE ______________
- ☐ OTHER ______________

REPORT PREPARED BY ______________ DATE OF REPORT __/__/__

DATE RECEIVED AT REGIONAL OFFICE __/__/__

MCH (4/84)

INSTRUCTIONS
IHAP Registration Form

General

1. This form is to be completed to register a child in the IHAP program as soon as possible after birth or hospital discharge.
2. Enter all information as appropriate and necessary to complete the form.
3. Submit the white and canary copies of the form to the appropriate Regional/Area office. Retain the pink copy for your records.

A. Identifying Information

1. Enter the infant's name in the appropriate spaces, as noted on birth record and/or hospital record/referral form. Indicate sex (M, F) of child, date of birth (month/day/year) and approximate gestational age (in *weeks*).
2. Enter hospital of birth and County where the hospital is located. If child was born outside a hospital note place (i.e., home), address (if applicable), County and State of location.
3. Enter residence of infant as noted on birth record and/or hospital record/referral form.
4. Enter mother's name(s) as noted on birth record and/or hospital record and enter her date of birth (month/day/year).
5. Indicate how this child became known to you. If you identified the infant through a review of birth records or hospital records, by *your* staff, please check the appropriate box (A or B). If the child was referred by a hospital, physician or the NYS Dept. of Health please check box (C, D or E). If the child was identified through other means, please indicate the name and title of the person/agency providing the referral.
6. For children that meet IHAP criteria, please check which criteria apply; for inherited metabolic diseases (IMD) and congenital anomalies indicate the specific condition diagnosed. For children receiving 10 or more days of premature nursery care, please indicate the child's primary diagnosis.
7. For children who do *not* meet IHAP criteria, please specify the principal indication for enrollment in the appropriate space. Do not enter information here if you responded to item six.

B. Report Prepared By:

Please enter your name, title and the date this report was prepared.

Birth

A Child is identified as being eligible for IHAP enrollment by meeting one or more of the criteria listed on the Registration Form (items # 6 & 7.). This criteria is currently being reviewed with input being solicited from across NYS for possible inclusions and changes. Sources of identification are noted on the Registration Form #5.

1 Month

Within this time home visit/assessment is conducted - no paperwork connected. As any needs problems, etc. are identified the county Public Health Nurse (PHN) utilizes her community knowledge to assist family in securing services.

6 Months

(Designated reporting period)

The Child is visited at home, using the Assement/Follow-up form the PHN interviews for all items. Any problems/needs noted in items F, G, H, & I require a referral to service in section J. Also, any previous services being utilized are reviewed as to status and this is reported. All sections of this form are completed included Developmental Screening Test and Anthropometry. If the child has a provider that is willing to cooperate with IHAP this information may be gleaned from that provider.

12 Months

(Designated reporting period)

Same as 6 months with the exception of the screening test. Any needs noted are referred.

2 Years

(Designated reporting period)

The child is visited at home by PHN or seen by the provider similar to age 1 year for general overall assessment & status check, no DST or anthropometry done. Any problems documented require referral.

3 Years

(Designated reporting period)

A Home visit is made by the PHN or the child is seen by a provider with the PHN serving as client - program manager in gaining information for follow-up. Total assessment done at this contact including DST and anthropometry, exclusive of head circumference unless a particular condition should warrant. All identified problems receive a referral

NOTE: At this time, if health care needs and other influential needs are being provided for and it is not anticipated that the child will have further problems and/or sequela to previous problems, closure to IHAP is recommended.

4 Years

If the PHN decides to continue follow-up, the child is visited at home or seen by the provider for a general assessment, parental interview, and overall status check. Once again, any noted problem areas are required to have a referral as itemized on the Assessment/Follow-up Form.

5 Years

Same as 4 years. In addition, this is the final contact under IHAP. Interview should focus on plans for school entry and any special needs of the child in that setting.

Additional Notes:

- o No parental consent required for participation, section 206.1J of the Sanitary Code gives State DOH the right to collect data.
- o If parents wish to discontinue their child's IHAP participation the case is closed.
- o Other reasons for closure are listed under "D" on the Change Form. This form is also used to update the master file in the event of any client change, such as name, address, etc.

- No legislative mandate exists for IHAP although the program is operating in every county on a contractual basis.
- The Funding source is the Maternal-Child Health Services Block Grant solely. The allocation this year was $1,750,000, apportioned to the contractors.
- Children developing noted delays subsequent to birth/newborn period are eligible for IHAP.
- Children diagnosed as terminally ill or those remaining institutionalized are registered and closed to continued follow-up.

NORTH CAROLINA

PURPOSE:

The rationale for the North Carolina High Priority Infant Program is the belief that early identification and tracking of infants at risk for disabling conditions improves their chances to benefit from intervention, thereby increasing the likelihood that they will reach their full developmental potential. Additionally, the program is viewed as a support not only to parents, but also to primary medical care providers. With the advent of Public Law 99-457, the program is considered the fundamental, statewide method for systematic identification of infants and families who may be served under the provisions of the law. Finally, the program represents an important public health response to the increasing numbers of low-birthweight infants who survive life-threatening conditions at birth and need to be followed closely at least during their first few years of life.

DESCRIPTION:

HISTORY: The original program, designed to track infants at risk for developmental delays and to assure that they receive medical supervision, has undergone two major revisions since 1979. The 1983 revisions in the program established categories of risk criteria and a corresponding protocol of home visits, tracking contacts, and assessments, according to each child's condition and the clinical judgment of his or her High Priority Nurse and primary care provider. Tracking reports were computerized and twelve-month follow-up evaluation for infants with high medical risk was added. In July of 1988, the program was revised again to broaden the risk conditions and to require that support services be offered to all enrolled infants. These latest changes are based on routine program reports, anecdotal evaluation from practitioners in the program, and improved knowledge about identification, tracking, assessment, and intervention process.

EFFECTIVENESS: Performance reports for the program suggest that some components of the protocol are performed more than others. For example, developmental screening and home visitation by nurses decrease as infants age. While it is clear that the program generally is being implemented as planned, performance is not at 100% of capacity. No outcome data have been collected to compare infants served by the program to other unserved infants.

The number of infants enrolled in the program has risen steadily since the 1983 revision to a high of 4868 infants in 1987. Over the years most infants have consistently been identified on the basis of biomedical conditions, however, by 1987 a substantial proportion of infants were enrolled on the basis of one or more environmental conditions. Since the 1983 revisions, the proportion of children referred to North Carolina's Developmental Evaluation Centers and Early Childhood Intervention Services from the High Priority Infant Program has risen steadily. Approximately 85% of infants in the program are reported to be receiving medical care according to twelve)month tracking reports.

The 1983 Program established a means of tracking developmental performance for a subset of the enrolled population. Standardized twelve-month follow-up findings on almost 800 enrolled infants who have had one or more of five medical risks in the newborn period (i.e. birthweight under 1501 grams, intracranial hemorrhage, seizures, meningitis, or neurological abnormality due to asphyxia), report that nearly half of these infants had one or more suspected or diagnosed abnormal developmental or neurological findings, reported by the end of their first year of life.

Overall, the program's reports data suggest that the North Carolina statewide system of identification and tracking of vulnerable infants is being successfully implemented. However, it is not known whether the system optimally identifies the majority of children who will have disabling conditions by age three. Similarly, no conclusions about the long-term effectiveness of the program on developmental outcomes of enrolled infants have been reached.

FUTURE PLANS:

The 1988 revisions in the program will extend tracking and developmental assessment to age three for infants not otherwise served by any of North Carolina's special programs (e.g. Developmental Evaluation Centers and Early Childhood Intervention Services). The latest changes also require intermittent parent-child assessment by High Priority Infant nurses, including methods adapted from Barnard's Nursing Child Assessment Training (NCAST) approach. Nurses will report the developmental conditions for all enrolled infants across several points in time.

North Carolina Department of Human Resources
Division of Health Services

HIGH PRIORITY INFANT IDENTIFICATION

1. Last Name First Name MI

2. Patient Number ☐☐☐☐☐☐☐☐☐ H

3. Date of Birth ☐☐ Month ☐☐ Day 1 9 ☐☐ Year

4. Race 1 = White 2 = Black 3 = Am. Ind. 4 = Other ☐

5. Sex 1 = Male 2 = Female ☐

6. County of Residence: ______________________ ☐☐☐

7. Hospital of Birth: ______________________ ☐☐☐

8. Birth Weight ☐☐ Pounds ☐☐ Ounces OR ☐☐☐☐ Grams

9. Gestational Age at Birth ☐☐ Weeks

10. Maternal Information:

Name: ______________________

Home Address: ______________________

____

Directions to Home: ______________________

____

____

____

Telephone Number: (   ) ______________________

11. Date of Report ☐☐ Month ☐☐ Day ☐☐ Year

12. Risk Conditions (Circle the code number of each condition identified. Refer to High Priority Infant Manual for definitions.)

PARENTAL/FAMILY CONDITIONS

100 Maternal age < 15 years
101 Maternal PKU
102 Mother HIV positive
103 Maternal use of anticonvulsant, antineoplastic or anticoagulant drugs
104 Parental blindness
105 Parental substance abuse
106 Parental mental retardation
107 Parental mental illness
108 Difficulty in parental/infant bonding
109 Difficulty in providing basic parenting
110 Lack of stable housing
111 Lack of familial and social support
112 Family history of childhood deafness

NEONATAL CONDITIONS

200 Birth weight < 1500 grams
201 Gestational age < 32 weeks
202 Respiratory distress (mechanical ventilator > 6 hours)
203 Asphyxia
204 Hypoglycemia (< 25 mg/dl)
205 Hyperbilirubinemia (> 20 mg/dl)
206 Intracranial hemorrhage
207 Neonatal seizures
208 Major congenital anomalies
209 CNS infection/trauma
210 Congenitally acquired infection

POSTNEONATAL CONDITIONS

300 Suspected visual impairment
301 Suspected hearing impairment
302 No well child care by age 6 months
303 Failure to thrive
304 Failure on standard developmental or sensory screening test
305 Severe chronic illness
306 Significant parental concerns
307 Diagnosed genetic disorders
308 Identified emotional or behavior disorder
309 Substantiated abuse/neglect

13. Attending Physician

I have reviewed this identification form and understand that the infant will be followed in the High Priority Infant Program.

Signature: ______________________

14. Infant's Primary Medical Provider

Name: ______________________

Address: ______________________

____

____

15. Parent's Permission: I have had the High Priority Infant Program explained to me orally and in writing and agree to having my child enrolled. I understand that enrolling my infant in this program requires sending certain personal and medical information, contained in our hospital records, to my primary medical provider, the health department in the county where my child was born, the county health department where I live, and the Developmental Evaluation Center. I understand that my infant and I will be periodically visited in my home by a public health nurse. I understand that I can withdraw my child from this program at any time.

Parent's Signature: ______________________ Date: ______________

DHS 3548 (7/88)
MCH (Review 7/91)

Part I (white) retained by High Priority Nurse Part II (pink) to Data Entry Clerk Part III (yellow) to Primary Medical Provider

PURPOSE: To enroll children in the High Priority Infant Program and to collect information on their risk conditions.

PREPARATION: This form is to be completed by the hospital newborn nursery nurse or public health nurse assigned responsibility for enrolling children in the High Priority Infant Program. ***Items that are shaded are to be completed by the health department in the county where the child resides.***

DISTRIBUTION: Newborn nursery personnel forward all IDENTIFICATION forms to the local health department. For a non-resident birth, the health department forwards the IDENTIFICATION form to the health department in the county where the child resides. For resident births, the High Priority Infant Tracking Nurse retains Part I. Part II is given to the Data Clerk for entry into the Health Services Information System. Part III is forwarded to the infant's primary medical provider.

INSTRUCTIONS: Numbers correspond to item numbers on the IDENTIFICATION FORM.

2. **Patient Number**: Enter the child's HSIS number. To be entered by the health department in the county where the infant resides.

3. **Date of Birth**: Enter the child's eight digit date of birth, e.g., May 1, 1988 = $\boxed{0\,5\,0\,1\,1\,9\,8\,8}$

4. **Race**: Enter the code number that corresponds to the child's race, e.g., black = $\boxed{2}$.

5. **Sex**: Enter the code number that corresponds to the child's sex, e.g., male = $\boxed{1}$.

6. **County of Residence**: Newborn nursery personnel write in the name of the county where the infant resides. The High Priority Infant nurse in the county of residence enters the three-character code for the hospital of birth. Refer to Appendix B in Manual.

7. **Hospital of Birth:** Newborn nursery personnel write in the name of the hospital where the infant was born. The High Priority Infant nurse in the county of residence enters the three-character code for the hospital of birth. Refer to Appendix C in Manual.

8. **Birth Weight**: Enter the infant's birth weight in pounds and ounces or grams, e.g., 7 pounds, 12 ounces = $\boxed{0\,7\,1\,2}$ or 900 grams = $\boxed{0\,9\,0\,0}$.

9. **Gestational Age at Birth**: Enter the gestational age of the infant at the time of birth, e.g., 35 weeks gestation = $\boxed{3\,5}$.

11. **Date of Report**: Enter the six digit date that the form was completed, e.g., July 1, 1988 = $\boxed{0\,7\,0\,1\,8\,8}$.

DISPOSITION: This form may be destroyed in accordance with the Programs Operational Records Standard of the *Records Disposition Schedule* published by the North Carolina Division of Archives and History.

REORDER INFORMATION: Additional copies may be ordered on the REQUISITION FOR MCH MATERIALS (DHS 1625) from:

Maternal and Child Health Branch
N.C. Division of Health Services
P.O. Box 2091
Raleigh, NC 27602-2091

North Carolina Department of Human Resources
Division of Health Services

HIGH PRIORITY INFANT PROGRAM TRACKING STATUS

1. Last Name First Name MI

2. Patient Number ☐☐☐☐☐☐☐☐☐ H

Complete only when making update/correction

3. Date of Birth ☐☐ Month ☐☐ Day 1 9 ☐☐ Year

4. Race 1 = White 2 = Black 3 = Am. Ind. 4 = Other ☐

5. Sex 1 = Male 2 = Female ☐

6. County of Residence: ☐☐☐

7. Date of Report ☐☐ Month ☐☐ Day ☐☐ Year

8. ID Number Change

To change patient ID, enter "4" in block and enter old ID number below ☐

☐☐☐☐☐☐☐☐☐☐ H

Complete each tracking

9. Tracking Interval (Enter A, B, C, D or E):

A = 2 Weeks Postdischarge
B = 4 to 5 Months
C = 12 to 13 Months
D = 18 to 19 Months
E = 30 to 36 Months (Close child to tracking) ☐

10. Child closed to tracking (Enter Y for Yes or N for No. Go to item 13 if No.) ☐

Complete only when closing to tracking

11. Child received services from an Early Intervention Program (Enter Y for Yes or N for No) ☐

12. Reason child closed to tracking (Enter D, P, F, M, E or A. Form completed unless reason is A.)

D = Doctor refusal to enroll/track
P = Parental refusal to enroll/track
F = Lost to follow-up
M = Moved
E = Child expired
A = Aged out of program (Complete items 13-15) ☐

Complete each tracking unless closed for reasons other than Aged Out

13. Child receiving well child care (Enter Y for Yes or N for No) ☐

14. Child's developmental status (Enter N, A, Q, or U. Go to item 15 if 18-19 or 30-36 mos. tracking interval.)

N = Normal
A = Abnormal
Q = Questionable
U = Unavailable/Unknown ☐

Complete only for 18-19 and 30-36 months tracking intervals

15. Child received intermediate assessment (Enter Y for Yes or N for No. Complete items 16 and 17 if No.) ☐

16. Child receiving special care from a DEC (Enter Y for Yes or N for No) ☐

17. Child receiving assessments from NICU Follow-up Clinic (Enter Y for Yes or N for No) ☐

DHS 3549 (7/88)
MCH (Review 7/91)

Part I (white) retained High Priority Nurse Part II (blue) to Data Entry Clerk

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PURPOSE: To record information concerning the developmental status and services received by children enrolled in the High Priority Infant Program.

PREPARATION: The High Priority Infant Tracking Nurse in the county where the child resides is responsible for completing the HIGH PRIORITY INFANT TRACKING STATUS REPORT. The form is to be completed on each high priority infant at two weeks postdischarge from the newborn nursery, and 4-5 months, 12-13 months, 18-19 months, and 30-36 months of age.

DISTRIBUTION: High Priority Infant Nurse forwards Part II to Data Entry Clerk and retains Part I.

INSTRUCTIONS: Numbers correspond to item numbers on the TRACKING STATUS REPORT.

2. **Patient Number**: Enter the child's HSIS number.

3. **Date of Birth**: Enter the child's eight digit date of birth, e.g., May 1, 1988 = [0|5|0|1|1|9|8|8]. Complete only when making a correction or update.

4. **Race**: Enter the code number that corresponds to the child's race, e.g., black = [2]. Complete only when making a correction or update.

5. **Sex**: Enter the code number that corresponds to the child's sex, e.g., male = [1]. Complete only when making a correction or update.

6. **County of Residence**: Enter the three digit county code where the child resides. Complete only when making a correction or update.

7. **Date of Report**: Enter the six digit date that the form was completed, e.g., July 1, 1988 = [0|7|0|1|8|8]

8. **Administrative Action**: Enter "4" when replacing or correcting a child's HSIS number. Also enter the child's old ID number.

DISPOSITION: This form may be destroyed in accordance with the Programs Operational Records Standard of the *Records Disposition Schedule* published by the North Carolina Division of Archives and History.

REORDER INFORMATION: Additional copies may be ordered on the REQUISITION FOR MCH MATERIALS (DHS 1625) from:

Maternal and Child Health Branch
N.C. Division of Health Services
P.O. Box 2091
Raleigh, NC 27602-2091

North Carolina Department of Human Resources
Division of Health Services

CHECKLIST AND REPORT FOR DEVELOPMENTAL EVALUATION CENTER INTERMEDIATE ASSESSMENT OF HIGH PRIORITY INFANTS

Name of Child: ______________________________ Date of Birth: ______________
Last First MI Month Day Year

Patient Number (if known): ______________ Chronological Age in Months: ________ Months

Date of DEC Intermediate Assessment: ______________ Adjusted Age in Months: ________ Months
Month Day Year

Parent(s)' Name(s): ______________________________

INTERMEDIATE ASSESSMENT PROCEDURES

(✓ = yes o = no)

Check one: ☐ 1st DEC Intermediate Assessment ☐ 2nd DEC Intermediate Assessment

Parent Interview, Chart Review and Basic Assessment Data:

____ 1. Parents' concerns (if any) listened to.

____ 2. All records in child's chart reviewed including past screening and assessment results.

____ 3. Height, weight, head circumference data (past and current) establish appropriate developmental growth pattern.

____ 4. DEC examiner is satisfied that hearing of child is adequate.

____ 5. DEC examiner is satisfied that vision of child is adequate.

Quality Responses on Denver Developmental Screening Test (DDST)

____ 6. Child relates in age-appropriate way to examiner during DDST.

____ 7. Child's activity level during DDST is appropriate for age.

____ 8. Child's reaction time to DDST tasks is appropriate for age.

____ 9. Quality of child's fine motor functioning during DDST is adequate.

____ 10. Quality of child's gross motor functioning during DDST is adequate.

Areas Requiring Attention Over and Above DDST Items:

____ 11. Child's emerging language skills are age-appropriate.

____ 12. Child's articulate skills are age-appropriate.

____ 13. Quality of muscle tone appears adequate in upper extremities, lower extremities, and in trunk.

____ 14. Child appears to use movements in symmetrical manner (e.g., uses left hand in manner similar to right hand).

____ 15. Parents are satisified with child's progress in all major areas.

____ 16. DEC examiner is satisfied that parents' concerns have been answered.

____ 17. Child's family environment seems emotionally secure and financially adequate.

FINDINGS AND RECOMMENDATIONS

18. DEC Intermediate Checklist Results (Items 1-17). Check one:

☐ The DEC examiner has concerns concerning this child's development based on the items on the Checklist and these concerns are sufficiently strong to warrant referral.

☐ The DEC examiner does not have concerns sufficiently strong enough to warrant referral but does have suggestions to make to parents.

☐ The DEC examiner does not have concerns based on the Checklist.

19. Denver Developmental Screening Test Results. Check one: ☐ N ☐ A ☐ Q ☐ U

20. Based on Denver results and/or Checklist concerns, the DEC examiner is referring this child to:

______________ (name) DEC Explanation: ______________

______________ (name) NICU Explanation: ______________

______________ (name) ECIP Explanation: ______________

______________ (name) Other Explanation: ______________

______________________________ ______________
Signature and Title of DEC Examiner Date

DHS 3682 (5/88)
Developmental Disabilities Branch (Review 5/90) Part I - Chart, Part II - HPIP Nurse, Part III - Referral, Part IV - Primary Physician

PURPOSE: To document the completion of required procedures for the Developmental Evaluation Center (DEC) Intermediate Assessment of the High Priority Infant and to report the DEC Examiner's findings and recommendations based on assessment.

PREPARATION: The DEC Examiner to whom the High Priority Infant has been referred is responsible for completing the Intermediate Assessment and recording his or her observations and findings next to each of the first nineteen items on the Checklist and Report. The DEC Examiner should complete Item 20 based on his or her recommendations for referral, suggestions to the child's parent(s), and the need for further explanation of referrals made. The initial Checklist and Report is to be completed for each High Priority Infant by the infant's eighteenth (18) month of life, and, if indicated, by the infant's thirty-sixth (36) month of life.

INSTRUCTIONS: Enter last name, first name, and middle initial of the High Priority Infant receiving the Intermediate Assessment. Enter the infant's date of birth, 9-digit patient identification number (if known), date of the DEC Intermediate Assessment, and the name(s) of the infant's parents.

Intermediate Assessment Procedures

The DEC Examiner checks the appropriate blank to indicate whether this is the infant's 1st (i.e., 18 months) or 2nd (i.e., 36 months) Intermediate Assessment.

The DEC Examiner checks "yes" or "no" next to each item under the following procedures, according to the child's performance and parent's responses:

1-5. Parent Interview, Chart Review, and Basic Assessment Data
6-10. Quality of Responses on Denver Developmental Screening Test (DDST).
11-17. Areas Requiring Attention Over and Above the DDST Items.

NOTE: The DEC Examiner may consult the following resources in the HPIP Supplemental Resources Manual:

Item 4: Hearing: HEAR Kit by M. Downs

Item 11: Language: Early Language Milestone Scale (ELM Scale) by J. Coplan.

Item 12: Articulation: Articulation Test Items for 2-3 year olds from the Preschool Language Scale, published by The Psychological Corporation.

Item 13: Muscle Tone: Scoring Sheet for the Infant Neurological International Battery (INFANIB) by P. Ellison.

Item 14: Movement: Scoring Sheet for the Infant Neurological International Battery (INFANIB) by P. Ellison.

Findings and Recommendations:

18. DEC Intermediate Checklist Results: Check the DEC Examiner's level of concern, based on the overall assessment.

19. DDST Results: Check the finding which reflects the child's level of performance on the DDST. (N = Normal, A = Abnormal, Q = Questionable, U = Unavailable/Unknown)

20. If the DEC Examiner is referring the child to a Developmental Evaluation Center, a Neonatal Intensive Care Follow-up Clinic, or an Early Childhood Intervention Program, cite the name of the program and the explanation for the referral. If the child is being referred to other agency/professional(s), cite the name(s) accordingly and the explanation for the referral.

The DEC Examiner signs and dates the Checklist accordingly.

DISTRIBUTION: The DEC Examiner retains Part I in the DEC client record, and forwards Part II to the HPIP Nurse, Part III to referral, and Part IV to the primary physician. Copies for other resources must be photocopied for distribution.

DISPOSITION: This form may be destroyed in accordance with the Developmental Evaluation Center Standard, Patient File of the *Records Disposition Schedule* published by the North Carolina Division of Archives and History.

REORDER INFORMATION: Additional copies may be ordered from:

Developmental Disabilities Branch
N. C. Division of Health Services
P. O. Box 2091
Raleigh, NC 27602-2091

North Carolina Department of Human Resources
Division of Health Services

HIGH PRIORITY INFANT PROGRAM
DEVELOPMENTAL EVALUATION CENTER INTERMEDIATE ASSESSMENT
SUMMARY FOR PARENTS

1. Name of Child: ______________________________
Last First MI

2. Date of Birth: ______________
Month Day Year

3. Patient Number (if known): ______________

4. Date of DEC Intermediate Assessment: ______________
Month Day Year

5. Parent(s)' Name(s): ______________________________

6. Findings: ______________________________

____

____

____

____

7. Suggestions: ______________________________

____

____

____

____

3. Agencies or Professionals to Contact:

Name: ______________ Phone: ______________
Address: ______________________________
____

Name: ______________ Phone: ______________
Address: ______________________________
____

Name: ______________ Phone: ______________
Address: ______________________________
____

____

Signature and Title of DEC Examiner Date

DHS 3683 (5/88)
Developmental Disabilities Branch (Review 5/90)

Part I - Chart, Part II - Parents

PURPOSE: To summarize the DEC Examiner's findings, suggestions, and referral information for the parent(s) of a High Priority Infant who received the Developmental Evaluation Center's Intermediate Assessment.

PREPARATION: The DEC Examiner completes the Summary for Parents based on his or her observations on the Checklist and Report of DEC Intermediate Assessment. Findings, suggestions, and referral information are summarized for parents according to their needs.

INSTRUCTIONS:

*1. Enter last name, first name, and middle initial of the High Priority Infant receiving the Intermediate Assessment.

2. Enter the infant's date of birth.

3. Enter the infant's 9-digit Patient Identification number if known.

4. Enter the date of the DEC Intermediate Assessment.

5. Enter the name(s) of the infant's parent(s) for whom this summary is intended.

6. Findings: Describe the infant's performance on the Denver Developmental Screening Test (DDST) and other procedures of the Intermediate Assessment in concise terms according to the parent's level of understanding.

7. Suggestions: If the DEC Examiner has suggestions for the infant's parents, such as learning activities or materials, note them according to the parent(s)' level of understanding.

8. Agencies or Professionals to Contact: If the DEC Examiner is referring this infant to an agency or professional, note the appropriate name, address and phone number for each source.

The DEC Examiner signs and dates the Summary to Parents accordingly.

DISTRIBUTION: The DEC Examiner retains Part I in the DEC client record and gives Part II to the infant's parent(s).

DISPOSITION: This form may be destroyed in accordance with the Developmental Evaluation Center Standard, Patient File of the *Records Disposition Schedule* published by the North Carolina Division of Archives and History.

REORDER INFORMATION: Additional copies may be ordered from:

Developmental Disabilities Branch
N. C. Division of Health Services
P. O. Box 2091
Raleigh, NC 27602-2091

OHIO

HISTORY:

Ohio's MATCH II Project to develop a merged data base for Health and Mental Retardation/Developmental Disabilities began in 1986. Two major child-serving agencies in the state of Ohio (the Ohio Department of Health and the Ohio Department of Mental Retardation/Developmental Disabilities) were awarded a SPRANS (Special Project of Regional and National Significance) grant from the federal Office of Maternal and Child Health (MCJ-393828-01-0). These two agencies collaborated to develop a mechanism via computer linkage for identification, referral, and tracking of young children (age birth to six years) with or at risk of developmental delays. Through local Child and Family Health Services (CFHS) well-child clinics and local County Boards of MR/DD, these two agencies provide primary health care and early intervention services to the target population. The MATCH II Project builds upon the accomplishments of two earlier projects in Ohio: MATCH (a maternal and child health information management system), and the Ohio Comprehensive Early Intervention System (a statewide collaborative planning model that also developed the *Ohio Curriculum* to train early intervention service providers and parents in interagency collaboration).

PURPOSE:

The objective of the MATCH II Project was to merge the databases of the statewide client information system of MR/DD and the client information files of the Child and Family Health Services (CFHS) clinics throughout the state. The merged system has the capability of (1) assessing numbers of clients in dual programs, (2) monitoring the rate of overlap among providers, and (3) identification, via microcomputer, of children with diagnosed or suspected health/developmental risk conditions observed by health care professionals during visits of families to CFHS clinics.

DESCRIPTION:

Early in 1988, the MATCH II Project began implementing an updated computerized identification, referral and tracking system (IRTS) in the CFHS clinics. This tracking system has been developed as an add-on application of the microcomputer based relational database software already in existence at each CFHS clinic in Ohio. It is important to note that the IRTS was designed specifically to be a locally-driven system.

Basic steps of this new process are outlined in Figure 1. Step 1 involves computerized selection of children (age birth to 6 years) with diagnosed or suspected risk conditions observed by health care professionals during visits of families to CFHS clinics. At Step 2, the computer generates a report showing those clients with suspected conditions in need of referral for early intervention (to such programs as the MR/DD center or home-based programs, Head Start, etc.). Clinic personnel initiate an interagency referral for individual children and families at Step 3. If clinics have a printer on site, staff have the option of automatically printing out a computerized referral form with the referral information (child's name, suspected condition, etc.) in place. Each referral form contains a follow-up section to be completed by the agency receiving the referral. As Step 4 of the process, this information is received from community providers and entered by clinic staff into the tracking system file. Obtaining feedback on the status of referrals made is one of the major benefits to health clinics for purposes of quality assurance. The final step is the generation of reminder letters for both providers and/or clients who do not respond to referrals. The computer also generates reports showing providers' responses, or referrals in need of further action. This information is extremely helpful at the local level, where interagency/consumer groups attempt to coordinate services and match infants and families in need of support and intervention to the most appropriate services. It is important to note that the system was designed so that very little staff time is required to utilize the IRTS. Thus, clinic staff may more effectively utilize their time analyzing the reports an follow-up when necessary.

ISSUES/BARRIERS:

Establishing a comprehensive, coordinated statewide service delivery system to meet the needs of young children who are developmentally disabled or at risk, and their families is an issue facing many policy makers and administrators. It is unfortunate that many existing service systems for this population are characterized by fragmentation, gaps in service, unnecessary duplication, and lack of coordination. The MATCH II Project's Ohio's attempt to address these issues.

FUTURE PLANS:

As the pilot MATCH II sites becomes more familiar with referral criteria, use of the system, and the other service providers at the local level, increasing numbers of mutual referrals between Health and MR/DD are expected. One unexpected outcome of MATCH II implementation at the local level is the increase in collaboration on behalf of children and families between Health and MR/DD. Pilot participants are identifying shared values and common issues. Together, they are exploring the potential for sharing information and resources to improve services. For example, in one community where public health nursing resources are scarce, the early intervention specialist from the County Board of MR/DD visits the CFHS clinic on a monthly basis to follow up on infants identified during clinic visits by health care professionals.

The IRTS has sparked community-wide collaborative efforts as well. Pilot participants have begun to share some of the reports generated by the IRTS with other service providers. The outcome will be enhanced coordinated identification, referral and tracking services for infants and their families.

The Relationship of the MATCH II Project to Public Law 99-457:

The MATCH II Project also state-level applicability. P.L. 99-457 requires that each state participating in Part H develop and implement a data collection system, central directory of statewide services, a comprehensive child find system a system for making referrals to service providers in a timely manner, and other components related to comprehensive early intervention services which will rely heavily on the ability to collect and analyze accurate information from a variety of sources. It is anticipated that MATCH II will be modified and expanded so that at the state level, data collected by various agencies will be linked, or merged, as was the data from Health and MR/DD. Currently, the linkage system utilized by MATCH and MATCH II includes records from the Child and Family Health Services Clinics, the Genetics Clinics, birth certificates, the Bureau for Children with Medical Handicaps, Medicaid, and MR/DD. In a state such as Ohio with a large population, coordination of existing data is essential for maximum program efficiency. The MATCH II Project is helping to evaluate one mechanism for ensuring more comprehensive, coordinated services.

Ohio Department of Health and
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MATCH II
IDENTIFICATION, REFERRAL & TRACKING SYSTEM

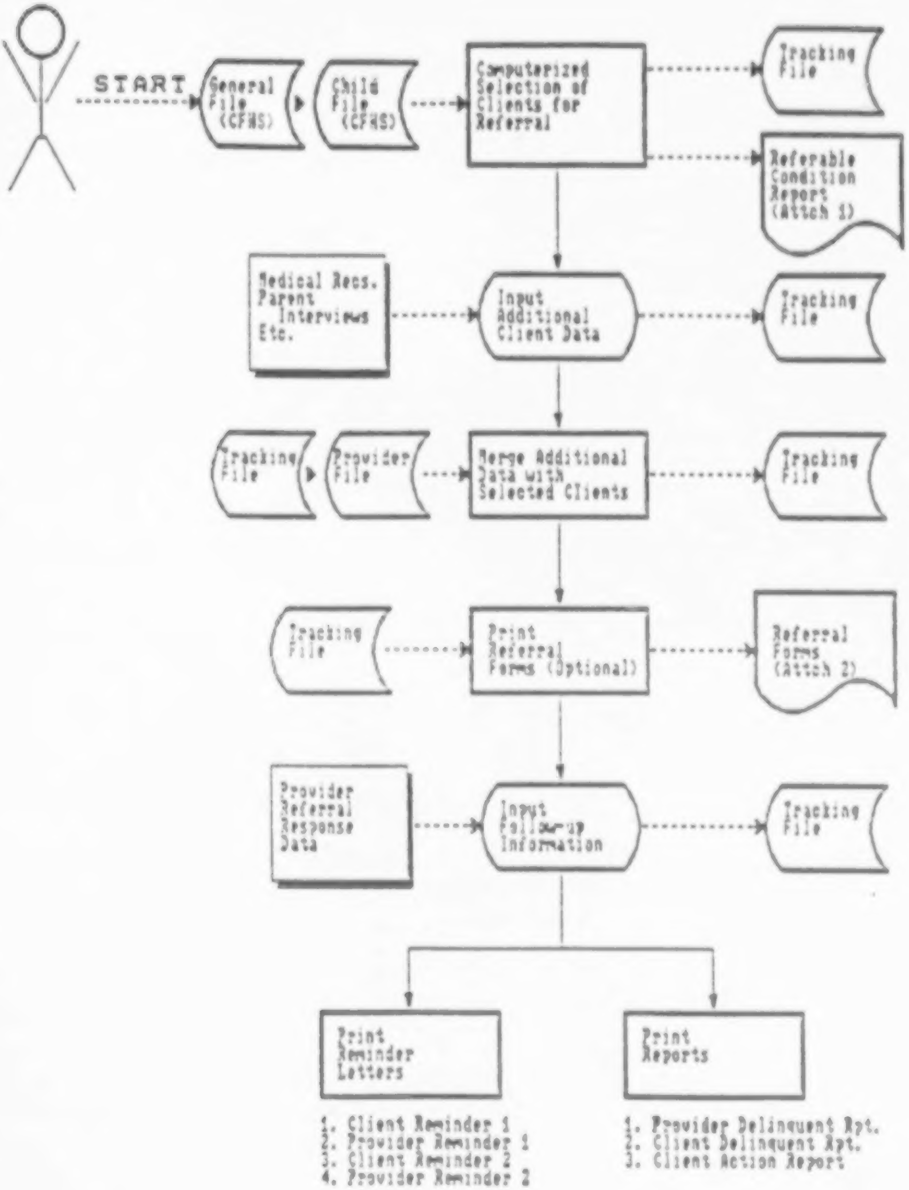
START
General File (CFHS)
Child File (CFHS)
Computerized Selection of Clients for Referral
Tracking File
Referable Condition Report (Attch 1)
Medical Recs. Parent Interviews Etc.
Input Additional Client Data
Tracking File
Tracking File
Provider File
Merge Additional Data with Selected Clients
Tracking File
Tracking File
Print Referral Forms (Optional)
Referral Forms (Attch 2)
Provider Referral Response Data
Input Follow-up Information
Tracking File
Print Reminder Letters
Print Reports
1. Client Reminder 1
2. Provider Reminder 1
3. Client Reminder 2
4. Provider Reminder 2
1. Provider Delinquent Rpt.
2. Client Delinquent Rpt.
3. Client Action Report

Figure 1.

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Retardation and Developmental
Disabilities, 8/88

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            MATCH II TRACKING FILE

Client Number:  CNO    _____________  Grant Mang No:  GMN    ____
         Site:  SITE   __                Visit Date:  VDATE  ________
  Provider No:  AGNO   ___          Case Manager No:  CASE   ____
    Birthdate:  BDATE  ________                 Sex:  SEX    _
  Parent Name:  PNAME  _________________________ Phone  PHONE  ____________
      Address:  ADDR1  _________________________
                ADDR2  _________________________

     Comments:  COMT1  ______________________________
                COMT2  ________________________________________

Appointment Date:  APPT  ________   Time:  TIME  ____

     Location:  LOCAT  ________________________________________

   First Name:  FNAME  ____________________
    Last Name:  LNAME  ____________________

   Conditions:  CCON1  _____   CCON2  _____   CCON3  _____   CCON4  _____

Provider Name:  AGNAME  _________________________
           Rep mode: Ins mode (INS), Del char (DEL), Erase field (F6)



Provider Addr:  AGADDR1  _________________________
                AGADDR2  _________________________
Contact Name:    AGCONT  _________________________
Phone No:       AGPHONE  _____________

********REMINDER INFORMATION**********

 1st Provider Reminder sent:  PRMD1  _  Date:  PDT1  ________
 2nd Provider Reminder sent:  PRMD2  _  Date:  PDT2  ________
 1st Client Reminder sent:    CRMD1  _  Date:  CDT1  ________
 2nd Client Reminder sent:    CRMD2  _  Date:  CDT2  ________

********RESPONSE INFORMATION**********

Received Provider Response:  PRCV  _  Date:  RCVDT1  ________
Received Client Response:    CRCV  _  Date:  RCVDT2  ________

Enrolled  ENRL  _             Not Eligible  NELG  _   On Waiting List  WAIT  _
Refused Service  REFUSE  _    Missed Appt  NOSHOW  _
Other  OTHR  _                Specify:  OSPEC  ____________________

Provider Comments:  PCOM1  ____________________________________________________
                    PCOM2  ____________________________________________________
           Rep mode: Ins mode (INS), Del char (DEL), Erase field (F6)
```

Ohio Department of Health and
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REFERRAL FORM
MATCH II Referral Network

From:		To:	
Name:	M. SUE BENFORD	Name:	JOHN SMITH
Agency:	MATERNAL & CHILD HEALTH	Agency:	AGENCY NUMBER 1
Address:	246 N HIGH ST. COLUMBUS OH	Address:	123 E MAIN COLUMBUS OH 43211

Child Name: MARK   Visit date: 07/16/87

Birthdate: 10/03/56   Sex: M

Child Client Number: 02-03363   GMN: 430-0   Site: B

Parent/Guardian Name: HORACE DUTTON   Phone: 216-674-7585

Address: P.O. BOX 65
MILLERSBURG OH

CFHS Referral for Early Intervention Suspected Conditions: 783.4

Other/Comments:

Date of Appointment: 11/21/87   Time: 10:00

Location: POMERENE HOSPITAL

NOTE:This Referral does not establish a diagnosis

****

Please use this space for Follow-up Report to Referring Agency:
Client Name: ______________________________ (Optional)

Check all that apply:
___ Enrolled in Program
___ Not Eligible Re-referred to: ______________________________
___ On Waiting List
___ Parent Guardian Refused Services
___ Family Did Not Keep Appointment
___ Other (please specify): ______________________________
____

Date: ___/___/___
Agency Name: ______________________
02-03363   430-0 B   07/16/87   Contact Person: ______________________

OREGON

Oregon's involvement with early intervention programs predates Public Law 99-457 by several years. In 1983 state law mandated a coordinating council and specified both programmatic and fiscal collaboration as well as record sharing between state Education and Mental Health agencies. As part of the planning and implementation of the state's Early Intervention program, 36 local (county based) councils were established. These councils have been invaluable in bringing together local health, mental health and human services agency representatives, as well as private sector providers and parents.

While a formal tracking system was not a specific component of the mandated services, through their involvement with the local councils the persons responsible for implementing such a system are already familiar with the concept of "tracking" and Public Law 99-457.

Planning and support for an integrated tracking system has been facilitated by the involvement of Oregon's Title V agency for Children with Special Health Needs (SCSHN). While not a legislated member of the Coordinating Council, the SCSHN was encouraged to participate. This agency already had a state-wide network and shared computer tapes have recently shown that the Title V agency had independently provided comprehensive health care planning for almost 60% of the children and families enrolled in the state's early intervention program. We believe this also suggests that in Oregon there may already be a higher degree of agency interaction than exists in some states.

A second circumstance which has helped to prepare the environment for a comprehensive, state-wide tracking system is the presence of two related and nationally recognized research activities. Both projects were designed to validate and determine efficacy of early infant assessment instruments and protocols. This first, reported by Nickel and Renken (DMCN 30: Sup. 57 pp 39, 1988) developed a reporting, assessment, and tracking system for high risk graduates of neonatal units in a seven county rural area of southern Oregon. This program called the "Oregon Developmental Monitoring Program (ODMP) involved hospital staff, private physicians, county health personnel and the state Title V agency to track and periodically assess over 500 infants at risk.

Using state and local resources, this program involves training of community health nurses to function as specialized assessors and care coordinators for children at risk. The program is being extended with state resources beyond the completion of research funding.

A second project, the "Infant Monitoring Program" (IMP) directed by Diane Bricker at the University of Oregon draws upon the expertise and observational abilities of parents through the use of developmental questionnaires. Infants eligible for the Infant Monitoring Program are infants determined to be "at risk" due to biological or environmental concerns. Most enrollees have spent some time in a neonatal intensive care unit. After enrollment, parents are mailed a series of questionnaires when their child reaches, 4, 8, 12, 16, 20, 24 months, 30 and 36 months of age. Each of the eight questionnaires is identical in format and covers five assessment areas: communication, gross motor, fine motor, adaptive, and personal-social. In addition, general questions regarding feeding, sleeping, and parental concerns are included. Parents who require additional assistance in completing or returning the form are contacted by telephone, and provided the option of completing the questionnaire via telephone. Completed, returned forms are then scored to determine the infant's or toddler's developmental status. Standardization of the parent questionnaires is underway. Early results indicate encouraging reliability and validity data. The cost of the parent questionnaires is extremely low, approximately $2.50 per questionnaire (Bricker, Squires, Kaminsky and Mounts, 1988).

These projects currently involves several rural counties or communities. Drs. Bricker and Nickel are collaborating to help the state planning body identify a set of appropriate screening instruments.

A third event fortuitously timed for the planning of a comprehensive case finding and tracking system was the advent of the Centers for Disease Control model birth certificate, implemented in Oregon, as in many states, in early 1989. While the national model embodies many new elements which will help identify newborns at risk, it did not have questions to identify risk for familial hearing loss. The Health Division's Maternal and Child Health program provided leadership in correcting this oversight and in the process developed a decision package for a coordinated system which has been endorsed in principle by the State Early Intervention Coordinating Council. The package was presented in the 1989 state legislative session. This planned system will build on the county health departments, many of which are already involved. A micro-computer network will tie counties to the state Health Department mainframe which in turn will be able to share appropriate data with state Educational, Mental Health, Social Service and Handicapped Children's agencies.

In addition to the participating agencies and groups which have been mentioned, the state medicaid and state social services agencies have also participated actively in planning for an integrated tracking system. As a consequence, the planned system will include the following agreed upon concepts:

- The "tracking system" will include and (and probably be limited to) screening, identification, and monitoring of infants at risk for developmental handicaps. (Diagnosis, evaluation, eligibility determination and long term coordination are beyond the scope of a "Tracking System").
- Inclusion in the tracking system will be with the agreement of patient and/or family.
- A single state agency will be responsible to supervise a common data repository which can be interactive with other state agencies and local public and private service providers. The agency responsible for data supervision will:
    a) Utilize and tie together existing resources (Local Health, Social Services, Primary care, Local Early Intervention councils, other).
    b) Provide for county centered functional data bases which are interactive with the state tracking system.
    c) Avoid duplication of existing resources.
- The "Tracking System" will include infants with risk factors detectable in the prenatal, perinatal and postnatal periods.
- For each period the system will be capable of tracking children with "Established", "Biologic" and "Environmental" risk.

The tracking system will be capable of monitoring children at risk over time and be able to track children with established defects being served by programs.

Infant Monitoring Project*

Child's name:

Date of birth:

Address, if different from mailing address:

City:

Phone:

Child's doctor:

Doctor's phone:

Who is filling out the questionnaire?

If someone helped you fill this out, who?

Today's date:

Please Complete This Form On:

Please Return This Form By:

		P A R Q	2 0			
(1-5)	(6-8)	(9-12)	(13-14)	(15-16)	(17-18)	(19-20)

Here are some questions about things children do. Your child may have already done some of them and there may be others she is not yet doing. On the following pages, please check the space that tells what your child has done and is doing now. If you are not sure she can do some of the activities, try the activity with her. Thank you for returning this as soon as possible.

If you have any problems filling out this form, please call:

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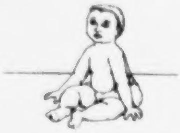
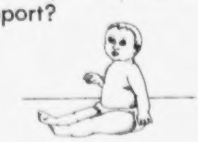
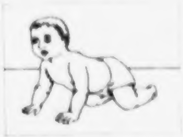
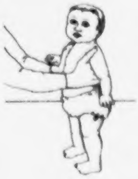
Eight Month Questionnaire**

I. COMMUNICATION (*Please try the activity if you are not sure.*)

	Yes	Some-times	Not Yet	
1. Does your baby make sounds you make by repeating them after you? (For example, a cough, a tongue-click, razz, etc.)	☐	☐	☐	___ 40
2. Does your baby make a sound like "da," "ba," "ka," or "ga"?	☐	☐	☐	___ 41
3. Does your baby combine two similar sounds like "ba-ba," "ga-ga," "da-da," even though he doesn't mean anything by them?	☐	☐	☐	___ 42
4. A "word" is a sound used consistently to mean a person, object, or group of objects. Does your baby say four words or more?	☐	☐	☐	___ 43
5. Does your baby look in the direction of your voice when you are out of sight?	☐	☐	☐	___ 44
6. Does your baby listen to the tone of your voice when you say "no, no" to him (although he may go ahead with what he was doing after pausing)?	☐	☐	☐	___ 45
7. When a loud noise occurs, does your baby turn to look where the sound came from?	☐	☐	☐	___ 46

II. GROSS MOTOR (*Please try the activity if you are not sure.*)

1. When you put him on the floor, does your baby lean on his hands while sitting? 	☐	☐	☐	___ 47
2. When you put him on the floor, does your baby sit up for more than 10 minutes without leaning on his hands for support? 	☐	☐	☐	___ 48
3. Does your baby get up on his hands and knees? 	☐	☐	☐	___ 49
4. When you hold him around the chest under the arms, does your baby support most of his weight while standing? 	☐	☐	☐	___ 50

** The content of this questionnaire was largely derived from the Revised Gesell and Amatruda Developmental and Neurological Examination (Knobloch, Stevens, Malone, 1980) and the Revised Parent Developmental Questionnaire (Knobloch, Stevens, Malone, 1980).

TEXAS:

The Texas Early Childhood Intervention (ECI) program is a comprehensive statewide program designed to serve all children from birth to three who are handicapped, developmentally delayed, or at risk for developmental delay. The Texas ECI program also serves children to age six if they are not eligible for the public school Early Childhood Education-Handicapped (ECE-H) program. Of the children enrolled in ECI, 96% are infants birth to three years old. The remaining 4% are 3-6 year olds who do not qualify for ECE-H program.

HISTORY:

The legislation establishing the ECI program mandated the state agencies (the Department of Health, the Department of Mental Health and Mental Retardation, the Department of Human Resources, and the Texas Education Agency), along with a parent representative appointed by the Governor's Office, to work together through an interagency council to carry out the intent of the legislation. The ECI Interagency Council has been the policy and decision-making body for the ECI program since 1981. In FY87, the ECI Interagency Council disseminated funds to 68 programs serving 10,175 children. The state administrative staff carries out the instructions of the council; monitors the 68 programs, provides them with training and technical assistance; and plans, conducts, and implements strategies for expanding services.

In 1981, when ECI was established, a tracking system was developed to collect information about the children enrolled for services. The entire system was abandoned four years later when it failed to yield information critical for planning and monitoring at the state level or essential to improving services at the local level. Two lessons were learned from that first attempt at tracking.

First, it was critical to distinguish between a management information system needed to provide data about children who are already enrolled in appropriate services and a tracking system that could follow children at risk for delay until their developmental situation resolved and tracking was no longer necessary or referral to an intervention program was appropriate. Texas needed a system to identify children who might need services from an ECI program and follow them until their needs were defined and a different system for children already enrolled in ECI programs. The first tracking project tried to combine both system into one and accomplished neither.

Second, the people using the data needed to be involved in the collection, compiling, and summarizing of the data. This was not the case in the original system. The Texas Child Find network was established as parent of Public Law 99-457. Since its purpose was to find children with special needs and enroll them in services it seemed logical to "piggy-back" an infant tracking system onto it. But the collectors, compilers, and summarizes of the Child Find system did not have a vested interest in the ECI system. It was just more work for them with no pay-off.

In 1986, the first attempt at a tracking system was abandoned and a management information system was implemented. Its purpose is to collect information about the state effort to provide services to children enrolled in ECI-funded programs. It provides data which can aid in planning at the state level and in justifying the ECI program to state legislators. Data for this system are not collected on each child at the state level. Rather, each program maintains information about its enrolled children and their families. The information is then aggregated by the program and reported to the state as a program performance report. The information is aggregated again across performance report. The information is aggregated again across programs to create a "state" picture of services. The system has been very effective in providing the information needed for state administration, but it dose not track children within ECI system. Within the next three years, ECI would like to establish a client-centered data base which could serve as an internal tracking system.

One of the major barriers to setting up an internal system is the interagency nature of the ECI program. Local services may be delivered through one of seven different agency affiliates; that is, local programs may be funded through private rehabilitation centers, local school districts, community Mental Health Mental Retardation centers, state schools, universities, community action programs, or private nonprofit agencies. Developing computer compatibility among these agencies has been a significant problem. Identifying personnel with computer expertise within ECI-funded programs has been another.

PILOT PROGRAM DESCRIPTIONS:

Two years ago, ECI began two pilot tracking projects which were designed to identify children at risk for developmental delay and follow them until they were enrolled in appropriate services or were dismissed from the system because they were no longer at risk for delay. A third tracking project was also funded to explore the feasibility of tracking babies in large metropolitan areas. Modeled after the Washington State High-Priority Infant Tracking System (HPIT), the primary goal of the Texas system is to identify children a t risk for developmental delay when they are born and ensure that they received regular and periodic developmental screenings. The Texas HPIT projects are designed to keep children connected to the medical community where developmental screenings can occur during well-baby checks.

A second goal of the pilot tracking projects was to determine the most feasible way for the state to administer and collect data from community-operated tracking projects. ECI decided that the Texas tracking effort would be most effective as a community-based, locally-operated system. A local interagency council was formed in each of two pilot communities. Each of the local councils is comprised of local physicians, hospital administrators, service providers, parents, and others whom the council considered important to the operation of the project. The local councils designed the model which they felt would be most effective in keeping children connected to health care and ensure developmental screening. In monitoring the formation of the local councils and their tracking projects, ECI began to determine which elements of a tracking system were critical to the state and required standardization across the state and which elements could be idiosyncratic to the community. Currently, ECI is developing a list of critical characteristics for Texas tracking projects. Once this list is complete and the parameters for systems have been established, ECI plans to expand the tracking projects to include 29 sites across the state, capturing 85% of approximately 300,000 annual births in Texas.

The state connection to the local interagency councils and therefore, the tracking systems is through the tracking coordinator. Once the local council has designed its project and ECI has reviewed and approved it, ECI awards the council funding to staff the project. In both pilots a tracking coordinator, data entry clerk, personal computer, and software were provided through the state award. The coordinator implements the system designed by the local council. Briefly both pilot projects flow as follows:

—All babies are screened for delay - established, biological, or environmental - at birth. Those with established delays are referred by the hospitals to programs for appropriate services.

—Babies at-risk of delay are placed on the tracking system. Risk is determined through a questionnaire. Questionnaires are mailed to the tracking coordinator, who enters children at risk onto the computerized data based system.

—At specific intervals the primary health care provider is notified that one of "their" babies was determined to be at risk at birth and should be screened carefully for possible delay.

—The physician returns a post card to the coordinator reporting the status of the baby. If the baby did not return to the provider for the well-baby check, the health care provider notes this and the tracking coordinator initiates procedures to locate the baby.

—The tracking coordinator alerts public health nurses that a baby at-risk did not receive the routine well baby check. The nurses search for the baby and encourage the parents to keep the appointment with the primary health care provider.

—If a child should require intervention services the tracking coordinator is available to the primary health care provider to assist in making a referral to the appropriate intervention program.

The two pilots differ in one significant aspect. The questionnaire in one system is completed by each infant's mother. In this project the high birth rate in the participating hospitals dictated parent participation. The hospital staff did not feel they could handle the initial screening as part of the hospital routine for newborns. In the second project the birth rate is much lower. Local physicians felt they should do the developmental screening. The protocols for each project are different, reflecting the medical emphasis in the one project and the parent control in the other.

A third project was funded in Houston in the spring of 1988. Each of two original projects were funded in medium-sized counties. Texas has four major metropolitan centers - Houston, Dallas, San Antonio, and Fort Worth. For a Texas tracking system to be truly successful a system must be designed that can work in large metropolitan areas. It is probable that the system used in these areas will be different from those implemented in the rest of the state.

ECI's challenge is to ensure that these systems interface and provide the data for justifying their continuation while allowing flexibility so that each system is responsive to and effective in meeting the needs of infants and their families and the professionals who provide them services.

HIGH PRIORITY INFANT TRACKING PROJECT   INFANTS CASE ID

_ _   _ _ _   _ _ _ _   _ _ _ _
REGION   COUNTY   HOSPITAL   INDIVIDUAL

PATIENT DATA

INFANT'S NAME ____
LAST   FIRST   MIDDLE

PLACE OF BIRTH
1.Hospital Code __________
2.Other ________________

DATE OF BIRTH ________________
GESTATION (weeks) ______________
DISCHARGE DATE ________________

INFANT'S SEX
Male ( )
Female ( )

MOTHER'S NAME ____
LAST   FIRST   MIDDLE

FATHER'S NAME ____
LAST   FIRST   MIDDLE

GUARDIAN,if any ____
LAST   FIRST   RELATIONSHIP

MIHIA PATIENT ( )YES   ( )NO

PRE-NATAL CARE
None ( )
1st Trimester ( )
2nd Trimester ( )
3rd Trimester ( )

INFANT'S ETHNICITY
Anglo ( )
Black ( )
Hispanic ( )
Other ( )

MOTHER'S AGE ______________________
GENERAL HEALTH ____________________
____
COMPLICATIONS IN PREGNANCY __________
____
TELEPHONE(______)_______-__________

ADDRESS ____
STREET or ROUTE NO.   CITY   COUNTY   ZIP

NAME OF PERSONS OTHER THAN PARENTS WHO WILL KNOW WHERE CHILD CAN BE LOCATED:

1.____
NAME   ADDRESS   TELEPHONE

2.____
NAME   ADDRESS   TELEPHONE

HIGH PRIORITY INDICATORS (CHECK ALL THAT APPLY)

( ) Birth weight < 2500 gms. or > 4500 gms.
( ) Birth weight < 10th %tile for gestational age (SGA)
( ) Head Circumference (OFC) < 10th %tile or > 90th %tile for gestational age
( ) Apgar score less than 4 at 5 minutes
( ) Congenital syphilis
( ) Ophthalmia neonatorum due to gonococcus
( ) Severe mental or psychosocial disorder of mother
( ) Preterm/Low birthweight (<1500 gms or < 35 weeks gestation)
( ) Large for gestational age (> 4500 gms or > 42 weeks)
( ) Respiratory distress syndrome (requiring ventilation > 2 hours)
( ) Other severe respiratory conditions (requiring ventilation > 2 hours)
( ) Endocrine or severe metabolic disturbance
( ) Severe digestive system disorder
( ) Neurologic abnormalities
( ) Severe congenital or genetic anomaly
( ) Mother 16 years of age or under   AGE:__________yrs.

BIRTH WEIGHT:____________gms.
WEIGHT AT DISCHARGE:____________gms.
HEAD CIRCUMFERENCE:____________in./cms
APGAR:____________
LENGTH:____________in./cms

( ) Drug/Alcohol abuse by mother
( ) Small for gestational age (<10%)
( ) Severe birth trauma
( ) Severe birth asphyxia (5 minute APGAR < 4)
( ) Severe perinatal infection
( ) Severe intraventricular hemorrhage
( ) RH isoimmunization
( ) Other jaundice requiring exchange transfusion
( ) Severe hematological disorders
( ) Convulsion
( ) Drug withdrawal syndrome in newborn

( ) Significant environmental, social, or parenting risk DESCRIBE:____________________________________
____
( ) Other specified severe medical condition____________________________________

FORM COMPLETED BY: ____ DATE ______________

I have reviewed the above information and believe it to be correct

____ DATE ______________
ATTENDING PHYSICIAN SIGNATURE (OR OTHER BIRTH ATTENDANT)

PARENT'S PERMISSION

I have had the "High Priority Infant Tracking Program" explained to me orally and in writing and agree to having my baby enrolled. I understand that enrolling my infant in this program requires sending certain personal and medical information as indicated above to my child's health care provider and to the local health department where my child resides presently or in the future. I understand I can withdraw my child from this program at any time. My child's health care provider is:

____
NAME OF HEALTH CARE PROVIDER

____
ADDRESS   TOWN   STATE   ZIP

____
PARENT'S SIGNATURE   DATE   WITNESS' SIGNATURE   DATE

( ) REFUSED TRACKING SYSTEM:____

CUESTIONARIO PARA EL DESARROLLO DEL RECIEN NACIDO

Regional Infant Screening Consortium

RISC

A NON-PROFIT INFANT SCREENING CONSORTIUM IN THE RIO GRANDE VALLEY

Un comité de doctores, enfermeras y maestros me han pedido hacerle algunas preguntas. Estamos intentando localizar a niños que posiblemente tengan inpedimentos a temprana edad. Si encontramos algún problema, se le avisará al médico de su niño o a su clínica de salubridad.

POR FAVOR, ESCRIBA CON LETRA DE MOLDE

Nombre del Bebé ______________________ Fecha de Nacimiento ________ Sexo ________

Nombre de los Padres ______________________ Teléfono ______________________

Domicilio ______________________ Ciudad ________ Codico Postal ________ (ZIP CODE)

Hospital/Clínica de Nacimiento ______________________

*Por favor escriba el nombre de la clínica de salubridad o al médico al cual tiene planes para llevar a vacunar a su hijo(a)

____

Estimado Padre de Familia: Favor de completar la información, marcando con un círculo SI o NO. Si necesita ayuda para contestar las preguntas, por favor pida hablar con la enfermera.

1. ¿Tiene Ud. más de 35 años o menos de 16? SI NO
2. ¿Ha tenido Ud. o alguien de su familia inmediata algún niño con problemas de oír, visión o algún otro problema grave? SI NO
3. ¿Tomó Ud. bebidas alcoholicas con regularidad durante su embarazo? SI NO
4. ¿Tuvo Ud. alguna enfermedad durante el embarazo, la cual requirió que tomara medicamentos, aun bajo prescripción médica? SI NO
5. ¿Durante su embarazo, estuvo en contacto con Rubeola o alguna especie de sarampion o enfermedad exantemática? SI NO
6. ¿Antes de, o durante su embarazo, estuvo tomando medicamentos para problemas mentales o nervios? SI NO
7. ¿Visitó Ud. al médico menos de tres veces antes del nacimiento de su bebé? SI NO
8. ¿Fué el parto tan difícil, que su bebé necesitó atención médica inmediata? SI NO
9. ¿Mientras su bebé estuvo en el hospital, tuvo él o ella:
   - a. una transfusión de sangre? SI NO
   - b. fototerapia por ictericia (una luz especial por tener la piel amarilla)? SI NO
   - c. necesidad de una máquina para respirar? SI NO
   - d. infecciones o enfermedades graves? SI NO
10. ¿Pesó su bebé más de 10 libras o menos de 4 1/2 libras? SI NO
11. ¿Tiene su bebé algún defecto de nacimiento? SI NO
12. ¿Se fué Ud. a casa antes que su bebé? SI NO

Por medio de la presente, autotizo yo al ______________________ para da la
(Nombre de la clínica u Hospital)

información de este cuestionario acerca de mi hijo(a), sin restricción, al Regional Infant Screening Consortium, al Centro de Lenguaje y Audición de Pan American University, al Médico de mi bebé o a la Clínica de Salubridad

______________________ ______________

Firma (Madre, Padre o Tutor Legal) Fecha

____

Testigo

NEWBORN DEVELOPMENTAL SCREENING QUESTIONNAIRE

Regional Infant Screening Consortium

RISC

A NON-PROFIT INFANT SCREENING CONSORTIUM IN THE RIO GRANDE VALLEY

I have been asked by a committee of doctors, nurses and teachers to have you answer a few questions. We are trying to find children who have possible developmental delays at a very early age. If there is a potential problem, your baby's doctor or health clinic will be notified.

PLEASE PRINT

Baby's Name ______________________ Birthdate ______________ Sex ______

Parent's Name ______________________ Phone No. ______________

Address ______________________ City ______________ Zip ______

Hospital/Birthing Center ______________________

Please list the name of the health clinic or the doctor's office where you plan to take your baby for immunizations

____

Dear Parent: Please fill out this information by circling YES or NO. ANSWER ALL QUESTIONS. If you need assistance, please contact the nurse.

1.	Are you over 35 or under 16 years old?	YES	NO
2.	Have you or anyone in your immediate family had children who have problems with seeing, hearing, or any other severe problem?	YES	NO
3.	Did you drink alcohol on a regular basis during pregnancy?	YES	NO
4.	Did you have any illnesses that required you to take prescribed medications during pregnancy?	YES	NO
5.	During your pregnancy, were you exposed to RUBELLA (3 day, German, or "soft" measles)?	YES	NO
6.	Before you were pregnant, or while you were pregnant, did you take any medication for emotional problems or mental disorders?	YES	NO
7.	Did you visit the doctor less than three times before the birth of your baby?	YES	NO
8.	Was this such a difficult delivery that the baby needed a doctor's immediate care after delivery?	YES	NO
9.	While your baby was in the hospital did he/she have:		
	a. a blood transfusion?	YES	NO
	b. A special light for jaundice?	YES	NO
	c. a breathing machine?	YES	NO
	d. infections or severe illnesses?	YES	NO
10.	Did your baby weigh over 10 pounds or under 4 1/2 pounds at birth?	YES	NO
11.	Does your baby have any birth defects?	YES	NO
12.	Did you go home before your baby?	YES	NO

I hereby authorize ______________________ to release the results of this
(Hospital or Birthing Center name)

questionnaire regarding my child, without limitation, to Regional Infant Screening Consortium, Pan American University Speech and Hearing Center, to my infant's physician, and/or prospective health clinic.

______________________ ______________
Signature (Mother, Father or Legal Guardian) Date

____
Witness

UTAH

UTAH REGISTRY FOR HANDICAPPED PERSONS (URH)

The Utah Registry for Handicapped (URH) is a computer assisted information system. It is not in and of itself a tracking system, but can be used by those developing or operating a tracking system to facilitate the centralization of information.

Utah is also developing other data systems. They are listed below with brief descriptions of the essential differences:

URH:

Gathers data from all public agencies regarding the services they have or are providing. Provides both individual and group data as output.

RESOURCE SYSTEM FOR FAMILIES OF HANDICAPPED IN UTAH:

This is a computer data base of resources available in Utah. It includes key data about the resource and is organized to facilitate retrieval of data based on the needs of the client. It will provide access through a hard copy manual, dial up modem, disk of personal computers or a toll free number. Components are in use and final system is scheduled to begin operation August 1, 1989.

HIGH RISK TRACKING:

This system will provide a registry type data base to identify and track at risk or handicapped before and until they are entered in a service program, using data from three sources: a revised birth certificate, a revised newborn screening form and a new reporting form to be used by all programs and providers. These forms are in various stages of development and are scheduled for implementation in sequence starting January 1, 1989 for the revised birth certificate to September 1, 1989 for the whole system. This system will be used for tracking and follow-up to assure that children are offered services when appropriate.

All of the public agencies are in various states of implementation of individual unified information management systems. These systems, and others not described, are designed to be compatible and interactive.

HISTORY:

One of the findings of the Handicapped Child Data Project of the Utah Department of Health was that a central, multi-agency information management system would be one of the most effective tools used to eliminate gaps in services to handicapped people, track and help guide them through a confusing sometimes conflicting system of services, and coordinate a multitude of agencies which often provide duplicate services. In addition, such a system could help plan future service, define accurate incidence rates and provide invaluable information for other research effort, sometimes tying into other registries, such as birth, death, genetics, genealogy and birth defects. The Central Registry for Handicapped is an ambitious project that has taken years to develop and will take years more to fully implement.

The Registry can be used for a multitude of purposes, including child find, case management tracking, planning, justifying services, program evaluation and other research.

First, the Registry will include the names and other demographic information, diagnosis, services provided, dates and places of services and contacts or resource people for handicapped persons served by the Utah Department of Social Services, the Utah Office of Education and Board of Education, and the Utah Department of Health. The ultimate goal is for Registry to include all handicapped individuals provided service by either public or private agencies in Utah. All age groups from birth to death will be covered. Eventually, the system will be totally interactive with frequent oversight reviews and continuous updating of information.

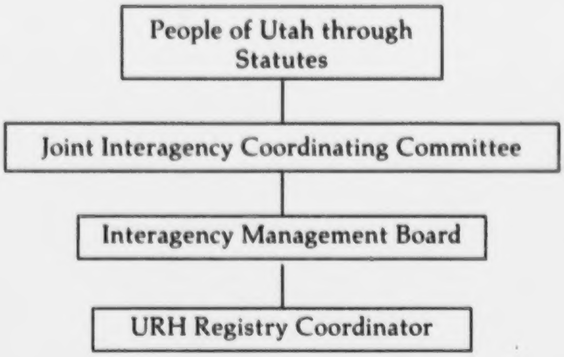
ACCOUNTABILITY:

Protection of the rights of confidentiality of those individuals on the Registry has been and is a major concern of this project. The legal and practical considerations of this problem have been worked out extensively and a brief summary of this issue follows.

The relatively free exchange of exchange of information between different agencies is based upon four principles. The first is that all of these public agencies derive their authority from society (the "state") through legislation. They are not separate entities but sub-units of a whole. Secondly, the individual has rights protected by the Constitution and the right to privacy is necessary in order to protect the others. Third, the individual may give up his right to privacy and does so to a degree specified when he obtains service. The key here is that he must be properly informed at this point that information will be shared, as necessary, to provide the services he agrees to. Finally, information is only shared as necessary to provide the services that have been legally authorized. Over-riding all of these principles is another. Information must be gathered and used to the extent necessary for an agency to fulfill its legal mandate. To do less would not only be inappropriate, it would be unethical if not illegal. Of course, such a brief summary cannot do justice to the issue and Utah has developed a much more extensive set of procedures to protect individuals in this sensitive area.

The Registry is physically housed in Education and the coordinator hired by Health. The Registry is under the direction of a Health, Social Services, Education (Interagency) Management Board chaired by Frederick I White, Ed.D. The Registry Director is Richard F. Gaufin, Ph.D.

Organizational Structure of the URH


People of Utah through Statutes
Joint Interagency Coordinating Committee
Interagency Management Board
URH Registry Coordinator

TIMETABLE:

Three documents about the Utah Registry for Handicapped Persons are in near-final form:

1. Revised System Documentation Manual. This is a technical document that describes the computer program and its operation.
2. Up-date to Policies, Organization, and Administration Manual.
3. Application and Procedures Manual. This is a user and informational manual derived from the first two documents. It will be of broad interest, and will be available for distribution by August 1989.

A Prototype of the Utah Registry for Handicapped Persons began operation at the end of July 1985. It has been revised and will be fully implemented by June 1989.

WASHINGTON

Washington State's efforts to identify and track infants at risk began in 1982 with a collaborative effort between the Washington State Department of Social and Health Services, Bureau of Parent-Child Health Services and the University of Washington Child Development and Mental Retardation Center (CDMRC). Two pilot counties served as "test sites" for development of the concept of tracking, data collection, and local resource coordination prior to statewide implementation.

PURPOSE:

The goal of the Washington State High Priority Infant Tracking Program (HPIT) is to establish a statewide system for the identification and tracking of infants at risk for poor health or developmental outcomes. The objectives are:

1. To help parents keep their child under the care of a primary physician.
2. To promote early identification of infants requiring further evaluation or services.
3. To assist in planning for the health and educational needs of the children of Washington State.

DESCRIPTION:

Any infant less than 30 days of age who meets one or more specific risk criteria in established, biological, or environmental risk categories is eligible, regardless of family income. Most infants (85%) are identified in local community hospitals, by nursing, medical, or social services staff. Regional perinatal centers also participate. When an infant is identified as a candidate for tracking, the parent(s) and the primary care provider must give permission in order for the next step to occur: tracking.

After identification and enrollment into the HPIT Program, the lead agency will contact the primary health care provider or agency (e.g., a pediatrician, public health clinic, or a community clinic) at 6, 12, 18, 24, and 36 months through a mailed questionnaire. This questionnaire obtains critical information for the ongoing medical and developmental monitoring of the child. The date of the last well child visit, specific information on the child's health and developmental status, and information regarding community services is obtained.

When a family fails to return to their "medical home" for a well child visit, active follow-up is initiated. The local community lead agency will attempt to reconnect the family with a primary health care provider through phone calls, letters, or home visits. Barriers to health care access are identified and attempts are made to resolve them. Only after extensive attempts at follow-up have been exhausted will a case be closed to tracking.

The HPIT Program is free to families who wish to participate. Local communities can receive 70 percent of the projected costs of the program from the Bureau of Parent Child Health Services. However, the HPIT Program cannot pay for well child visits, transportation, or intervention services. The HPIT Program only provides identification, monitoring, and surveillance services.

The HPIT Program connects high priority infants and their families to services in their communities in three ways. First, early identification of infants with risk factors can facilitate discharge planning that might include referral to community services such as parent to parent support groups, specific follow-up clinics, or service providers. Second, the HPIT Program has been shown to increase the number of maternal child health nursing referrals through the local county health district. Third, each completed tracking from is reviewed by the lead agency. Infants and families that may require further evaluation or intervention can be identified in this manner. Collaborative referrals for these services can be facilitated through the lead agency and the primary care provider.

For Washington State, HPIT is envisioned as the foundation for the development of a comprehensive, coordinated statewide system of childfind as one of the required components of Public Law 99-457. The HPIT Program is a key component in the childfind system because it identifies potential users of services and can facilitate referral for further evaluation and diagnosis of special needs.

ISSUES/BARRIERS:

At the present time only 16 of the 39 counties in Washington State have, or are in the process of developing active HPIT programs. Further expansion of the program is dependent upon additional state funding. Only state dollars directed to the Bureau of Parent Child Health Services are used to fund the program. These monies, combined with local level contributions provide the operating revenue of the program.

The development, implementation and maintenance of a computerized data entry and management system has proved to be expensive in terms of both time and resources. All participating programs are expected to maintain a local database, sharing aggregate information with state periodically. This process has presented significant concerns in the areas of technical assistance, consistency, and confidentiality.

As a system that intimately involves the local primary care providers, HPIT has continued to provide ongoing support and consultation to the local medical and health care community related to early identification and community services. The success of the program at the local level is often determined by the level of participation and sophistication of the health care providers in the community.

FUTURE PLANS:

Expansion of the HPIT Program statewide is anticipated during the next two years; this is dependent upon additional funding.Concurrent with these efforts ongoing refinement and expansion of the data system are planned.

Additional plans include ongoing review of the eligibility criteria, potential expansion of the enrollment period, and physician permission for enrollment. In response to the need for program information to be culturally sensitive, a series of videotapes utilizing native speakers is under development.

DEPARTMENT OF SOCIAL & HEALTH SERVICES

HIGH PRIORITY INFANT IDENTIFICATION

SENT TO - CASE NUMBER		
HOSPITAL	CLIENT	TIE BREAKER

SECTION A

CHILD'S NAME - last, first, middle

DATE OF BIRTH	GESTATION (WEEKS)	☐ MALE ☐ FEMALE	BIRTH WEIGHT IN GRAMS	BORN IN THIS HOSPITAL? ☐ YES ☐ NO	IF NO, WHERE?

MOTHER'S NAME - last, first, middle	AGE
FATHER'S NAME - last, first, middle	AGE
GUARDIAN'S NAME (if any) - last, first, middle	RELATIONSHIP

ADDRESS	CITY	COUNTY	ZIP CODE	TELEPHONE

NAME OF OTHER PERSON WHO KNOWS WHERE CHILD CAN BE LOCATED 1	ADDRESS	TELEPHONE
NAME OF OTHER PERSON WHO KNOWS WHERE CHILD CAN BE LOCATED 2	ADDRESS	TELEPHONE

INSURANCE? ☐ YES ☐ NO TYPE: ☐ PRIVATE ☐ MEDICAID ☐ CHAMPUS ☐ UNKNOWN ☐ OTHER ____________

SECTION B PRENATAL/MATERNAL FACTORS - *HIGH PRIORITY INDICATORS (CHECK ALL THAT APPLY)*

☐ 3 or less prenatal visits ☐ Maternal history of communicable disease (see back) ☐ Mother 15 years of age or younger

INFANT MEDICAL FACTORS - *HIGH PRIORITY INDICATORS (CHECK ALL THAT APPLY)*

- ☐ Birth weight ≤ 2000 GRAMS (4 lbs. 7 oz.)
- ☐ Birth weight ≤ 10th %tile for gestational age (SGA)
- ☐ Head Circumference (OFC) ≤ 3rd %ile or ≤ 2 SD below the mean for gestational age
- ☐ Apgar Score 3 or less at 5 minutes
- ☐ Seizures
- ☐ Intracranial hemorrhage
- ☐ Clinical Impression of possible neurological abnormality *(refer to back) DESCRIBE: ____________
- ☐ Major Birth defect or possible syndrome *(refer to back) DESCRIBE: ____________
- ☐ Significant Respiratory Distress *(refer to back) DESCRIBE: ____________
- ☐ Congenital or Acquired Infection: ____________
- ☐ At increased risk for HEARING IMPAIRMENT *(refer to back)
- ☐ At increased risk for VISUAL IMPAIRMENT *(refer to back)
- ☐ Confirmed congenital metabolic disorder (e.g. PKU, Hypothyroid) ____________
- ☐ Other medical problems. DESCRIBE: ____________
- ☐ ENVIRONMENTAL/SOCIAL FACTORS *(refer to back) DESCRIBE: ____________
- ☐ PARENTING FACTORS *(refer to back) DESCRIBE: ____________

FORM COMPLETED BY	DATE	HEALTH CARE PROVIDER'S SIGNATURE AT DISCHARGE ENROLLMENT	DATE

SECTION C PARENT'S PERMISSION

I have had the "High Priority Infant Tracking Program" explained to me orally and in writing and agree to have my baby enrolled. I understand that enrolling my infant in this program requires sending certain personal and medical information as indicated above to my child's health care provider and to the local health department or coordinating agency in the county where my child resides presently or in the future. **(I understand I can withdraw my child at any time within the three year period of the program.)**

☐ I give my permission to share information as needed with local health and social service agencies, local school district or educational service district

NAME OF PRIMARY HEALTH PROVIDER

ADDRESS	CITY	STATE	ZIP CODE
WITNESS' SIGNATURE	DATE	PARENT'S SIGNATURE	DATE

☐ Parental refusal of tracking system

Reason ____________ Date Received ____________ Public Health Nurse Initials ____________

DSHS 13-570 (REV. 3/89) *6 DISTRIBUTION: CANARY - Health Department/Lead Agency PINK - Hospital WHITE - Primary Care Provider

HIGH PRIORITY INFANT IDENTIFICATION INSTRUCTIONS

This form assists in identifying and tracking high priority infants in an effort to assure early ongoing care and attempts to improve any identified developmental disabilities.

Hospital personnel and/or attending physician completes this form for each infant meeting at least one of the high priority indicators.

Complete the form immediately after the identification of the infant to facilitate obtaining parental consent.

INSTRUCTIONS FOR COMPLETION

Section A - Patient Data:

Enter infant's case number, hospital number, client case number and tie-breaker for infant.

Enter infant's complete name, date of birth, gestation period, gender, and weight. Indicate whether born in this hospital or elsewhere.

Give mother's full name, age, address and telephone number. Give father's full name, age, address and telephone number. If child has a guardian, give guardian's name, relationship to child, address and telephone number.

List names, addresses and telephone numbers of other persons who would know the child's whereabouts if the parents or guardian could not be located.

Indicate if infant has insurance and the type.

Section B - High Priority Indicators:

Prenatal/Maternal Factors - check all boxes that apply.

Note: Check 'Communicable Disease' only if mother has been exposed to, or has a history of communicable disease. (such as: HIV, STD, Hepatitis - all types)

Infant Medical Factors - check all boxes for appropriate indicators using the following guidelines.

Clinical Impression of Possible Neurological Abnormality - refers to the observation/documentation of one or more of the following behaviors or conditions: jitteryness; weak/poor suck; regurgitation or other feeding problems; low/high muscle tone; tremors; abnormal primitive reflexes; or alteration in consciousness.

Major Birth Defect or Possible Syndrome - includes defects and syndromes which may impair later health and or development. Report suspected syndromes which may later be verified by chromosomal study or laboratory testing.

Significant Respiratory Distress - includes perinatal asphyxia, recurrent apnea, use of prolonged mechanical ventilation, pneumonia and pneumothorax.

Hearing Impairment - risk factors include but are not limited to: positive family history of hearing loss, asphyxia, meningistis, congenital/perinatal infections, head and neck defects, prolonged elevated bilirubin < 1500 grams birthweight and use of ototoxic drugs.

Visual Impairment - risk factors include but are not limited to: positive family history or congenital visual impairment; congenital perinatal infections and retinopathy of prematurity.

Environmental/Social Factors and Parenting Factors - require professional judgment to determine the presence of actual or potential risk factors. The Procedures Manual provides definitions and examples. Describe any relevant situation not specifically mentioned.

Form Completed By - person who fills out the form signs and dates.

Health Care Provider at Discharge/Enrollment - signs and dates. The signer may be the county health officer or the provider completing the enrollment/discharge examination at the hospital or at a well child clinic.

Section C - Parent's Permission:

Parent signs and dates giving permission for tracking program. Worker assures that an independent individual witnesses the parent's signature and completes health care provider's name and address.

Checks box to indicate parent's reason for refusal if parent refuses the tracking system. Public Health Nurse (PHN) dates and initials.

Distribution:

Send white copy to Health Department/Lead Agency. Hospital retains the canary copy. Send the pink copy to the primary health care provider.

DSHS 13-570 BACK (REV 3-89) *6

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DEPARTMENT OF SOCIAL & HEALTH SERVICES

HIGH PRIORITY INFANT TRACKING

SENT TO - CASE NUMBER		
HOSPITAL	CLIENT	TIE-BREAKER

SECTION A	CHILD'S NAME - last, first, middle		DATE OF BIRTH
PARENT'S NAME			TELEPHONE
ADDRESS *(SEE REVERSE)	CITY	COUNTY	ZIP CODE
AGENCY		ATTENTION	
ADDRESS			TELEPHONE

TRACKING CONTACT: ☐ 6 MONTHS ☐ 12 MONTHS ☐ 18 MONTHS ☐ 24 MONTHS ☐ 36 MONTHS

SECTION B LEAD AGENCY USE

I. INTERVENTION SERVICES

Is the child, or his or her family currently using any community services?

☐ No ☐ Unknown ☐ Yes, Specify:

☐ Health Department Services ☐ Women, Infants and Children (supplemental food program)

☐ Referral to physician or specialty clinic, specify ______

☐ Consultation/Evaluation Services, specify: ______

☐ Physical/Occupational threrapy ☐ Speech/Language Therapy

☐ Early Intervention Services ☐ Counseling Services ☐ Child Protective Services ☐ Parent Support Group ☐ Parent Education

☐ Home Health Services ☐ Other, specify: ______

If no services are used, please indicate reason:

☐ Family refused ☐ Family managing problems ☐ Services not available in this community ☐ Inadequate finances

☐ Awaiting services ☐ No services needed ☐ Not appropriate for child's needs ☐ Unknown

SECTION C PHYSICIAN USE - TRACKING DATA

II. Is the child still receiving comprehensive care from you? ☐ YES ☐ NO

Date last seen by you *(see back) ______ If no, indicate reason

☐ Unknown ☐ Cannot locate ☐ Acute care only ☐ Not appropriate ☐ Inadequate finances ☐ Late for checkup ☐ Deceased

☐ Moved to ______

☐ Referred to another physician: ______

Address ______

☐ Other ______

III. HEALTH STATUS ☐ Normal ☐ Other If other, check significant problems and specify below

☐ A CNS ☐ Cerebral Palsy ☐ Seizures ☐ Hydrocephalus ☐ Structural defects, specify

☐ B Pulmonary, specify ______

☐ C Cardiac, specify ______

☐ D Renal, specify ______

☐ E GI, specify ______

☐ F Growth disorders

☐ Poor pattern of weight gain ☐ Head circumference (≤ 3rd or ≥ 97th %ile) ☐ Other, specify ______

☐ G Sleeping/Feeding, specify ______

☐ H Malformation or Syndrome, specify ______

☐ I Sociomedical

☐ Child abuse/Neglect ☐ Other ______

☐ J Other, specify ______

IV. BEHAVIORAL/SENSORY DEVELOPMENT

Information obtained from ☐ Parent ☐ Observation ☐ Evaluation, specify ______

☐ Other, specify ______

A. Developmental Milestones - based on age (corrected for prematurity)

☐ No concern at this time ☐ Concern in the following areas:

☐ Personal-social ☐ Fine motor ☐ Gross motor ☐ Language ☐ Mental

B. Vision ☐ Normal ☐ Abnormal, specify ______

C. Hearing ☐ Normal ☐ Abnormal, specify ______

D. Other, specify ______

SECTION D FOLLOW-UP

COMMUNITY HEALTH FOLLOW-UP

Date notified child not in care ______

☐ # of letters sent

☐ # of telephone contacts

☐ # of attempted/completed home visits

☐ # of case conferences attended

SECTION E CASE CLOSURE

FOR PHN ONLY

Date of closure ______

Reason: Moved out of ☐ County ☐ State ☐ Country

☐ Parental permission withdrawn ☐ Deceased

☐ Physician permission withdrawn ☐ Completed Program

☐ Cannot locate

DSHS 13-563 (REV. 3/89) *6 DISTRIBUTION: WHITE - HEALTH DEPARTMENT/LEAD AGENCY CANARY - PRIMARY CARE PROVIDER

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HIGH PRIORITY INFANT TRACKING INSTRUCTIONS

This form assists in accumulating information concerning care received by high priority infants/families, and maintaining care for individual families. It provides indicators of those infants vulnerable to later developmental difficulties.

When the high priority infant is 6, 12, 18, 24 and 36 months of age (chronological), the local coordinating agency where the infant resides sends the High Priority Infant Tracking form to the designated primary health care provider. After the form is completed return it to the lead agency.

INSTRUCTIONS FOR COMPLETION

Section A - Patient Data:	Enter infant's case number, hospital number, client case number and tie-breaker for infant. Enter infant's complete name, date of birth, parent's full name, telephone number and address. If the address is different than the original address on the identification form for the child, so indicate. Check the appropriate box for the tracking contact period.
Section B - Lead Agency Use:	**Intervention Services:** Review services with family if possible. Check all that apply. If no services are used, indicate 'no' and the reason for no services.
Section C - Physician Use:	**Date Last Seen:** Each tracking form is intended to cover only the time period since the last form was completed, (e.g. the one year tracking form covers the six month period since the completion of the 6 months tracking form). If the child has not been seen since the last tracking period, record the date last seen by you. The lead agency will then provide follow-up and attempt to return the family to your care. **Health Status and Behavior Sensory Development:** Check appropriate indicators and provide descriptions as necessary. If the problem has resolved, do not report. If there is an ongoing problem requiring care, report on all tracking forms. Indicate which tool(s) has been used to assess behavioral/sensory development.
Section D - Followup:	Lead agency completes for the appropriate tracking period.
Section E - Case Closure - Reason:	This indicates that no future tracking activities will take place on this case from this agency. Enter reason (e.g. moved out of state or county; cannot locate parental permission withdrawn, etc.) Closure can take place at any time - even at the time of birth if it is apparent at that time that the child will not be tracked at all. IF INFANT MOVES TO ANOTHER COUNTY IN WASHINGTON, THE TRACKING FORM IS FORWARDED TO THAT COUNTY FOR TRACKING PURPOSES.

DSHS 13 569 BACK (REV 3 89) '6

High
Priority
Infant Tracking
Program

Questions and Answers about the Washington State High Priority Infant Tracking Program
Serving Washington's Youngest Citizens

1. **What are the program goals and objectives?**

The goal of the Washington State High Priority Infant Tracking Program is to establish a statewide system for the identification and tracking of infants at risk for poor health or developmental outcomes.

The objectives are:

1. To help parents keep their child under the care of a primary physician.
2. To promote early identification of infants requiring further evalution or services.
3. To assist in planning for the health and educational needs of the children of Washington State.

2. **Who is eligible and how are they identified?**

Any infant less than 30 days of age who meets one or more specific risk critiera in established, biological, or environmental risk categories is eligible, regardless of income.

3. **How are eligible infants identified?**

Most infants (85%) are identified in local community hospitals, by nursing, medical, or social services staff. Regional perinatal centers are also participating.

When an infant is identified as a candidate for tracking, the parent(s) and the primary care provider must give permission in order for the next step to occur - tracking.

4. **What occurs during the tracking phase?**

After identification and enrollment into the HPIT program, the lead agency will contact the primary health care provider (who might be a pediatrician, public health clinic or a community clinic) at 6, 12, 18, 24 and 36 months through a postal questionnaire.

This questionnaire obtains critical information for the ongoing medical and developmental monitoring of the child. The date of the last well child visit, specific information on the child's health and developmeptal status, and information regarding community services is obtained.

5. **What happens when a family and their high priority infant fail to return to health care?**

When a family fails to return to their "medical home" for a well child visit active follow-up is initiated. The local community lead agency will attempt to reconnect the family with a primary health care provider through phone calls, letters, or home visits. Barriers to health care access are identified and hopefully resolved. Only after extensive attempts at follow-up will a case be closed to tracking.

6. **Who pays for the Program?**

The HPIT Program is free to families who wish to participate. Local communities can receive 70% of the projected costs of the program from the Bureau of Parent Child Health Services. However, the HPIT program cannot pay for well child visits, transportation, or intervention services. The HPIT program provides identification, monitoring, and surveillance services.

7. **How can the HPIT Program connect high priority infants and their families to services in their communities?**

First: Early identification of infants with risk factors can facilitate discharge planning that might include referral to community services suchas parent to parent support groups, specific follow up clinics or service providers.

Second: The HPIT Program has been shown to increase the number of maternal child health nursing referrals through the local county health district.

Third: Each completed tracking form is reviewed by the lead agency. Infants and families that may require further evaluation or intervention can be identified in this manner. Collaborative referrals for these services can be facilitated through the lead agency and the primary care provider.

8. **Can an infant be identified and enrolled after 30 days of age?**

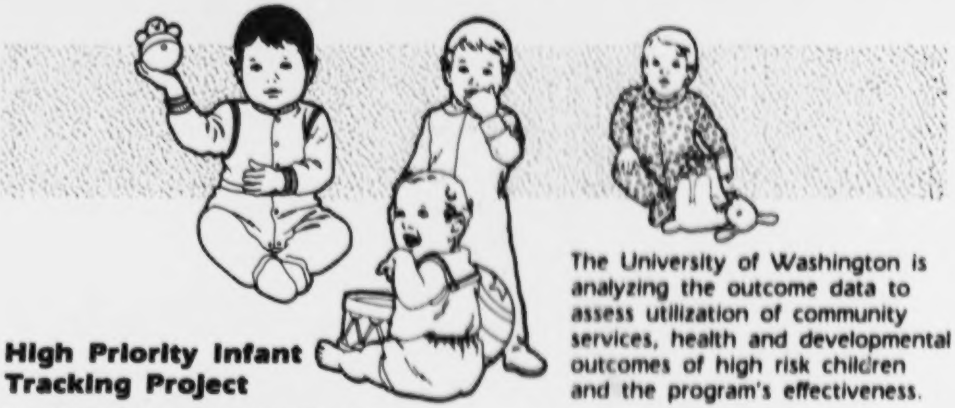
No, current funding is not available for this service. However, open enrollment for the program is under consideration.

Do You Know . . .

- that approximately 5,800 infants (8% of all births) born annually in Washington State suffer from adverse biological events during prenatal and perinatal periods?
- that low birthweight infants and those experiencing serious birth complications are at increased risk for developing problems such as cerebral palsy, delayed development, or learning disabilities? As many as 34-40% of very low birthweight (less than 1500 grams) infants may experience these problems.
- that only a community that promotes strong, cooperative working relationships between health, education and social services professionals and agencies can hope to meet the needs of high risk and disabled children?

High Priority Infant Tracking Project Objectives

1. To help parents keep their child under the care of a primary physician.
2. To promote early identification of infants requiring further evaluation or services.
3. To assist in planning for the health and educational needs of the children of Washington State.



High Priority Infant Tracking Project

The HPIT project was initiated in October 1982 by the Washington State Department of Social and Health Services, Office of Maternal and Child Health Services in cooperation with the University of Washington. It began as a pilot project in Whatcom County. Thurston County was added in May 1984.

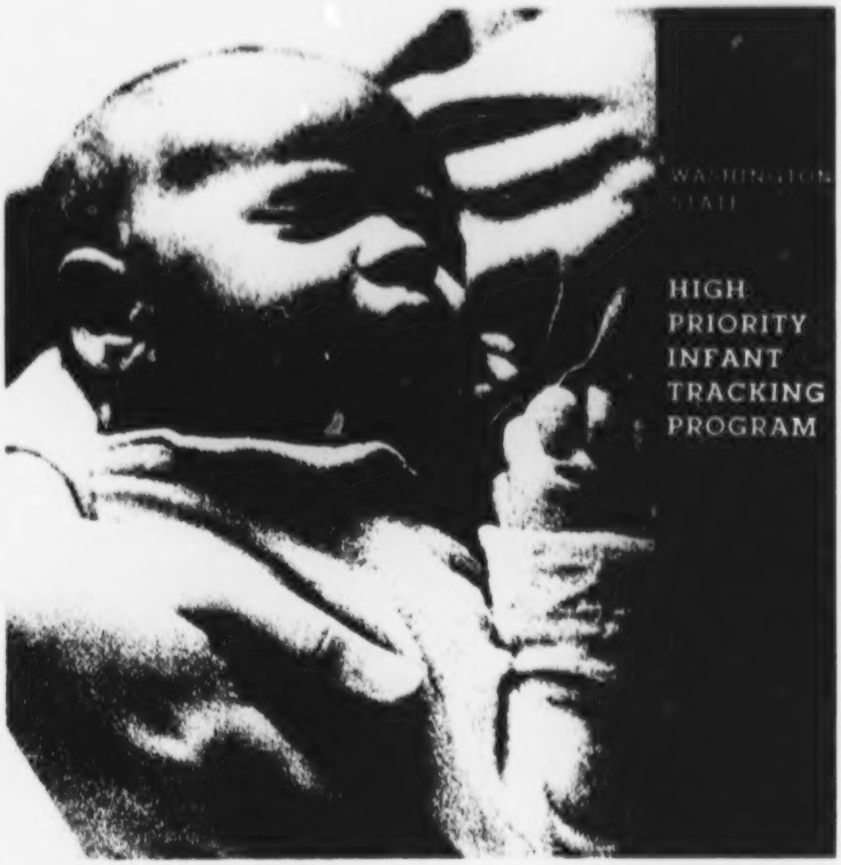
Infants from birth to three years who are at risk for chronic health and/or developmental problems due to biological or environmental risk factors are identified by physicians, nurses, or health department personnel. At regular intervals, the primary care provider is contacted to determine whether the child is still in care and what his/her health and developmental status is. If a child is found to have dropped out of care, the public health nurse assists the family in obtaining primary health care.

The University of Washington is analyzing the outcome data to assess utilization of community services, health and developmental outcomes of high risk children and the program's effectiveness.

What can a tracking system do?

An organized and coordinated system can . . .

- **Ensure** that **children** at high risk for chronic health or developmental problems **continue to receive regular preventive health care.**
- **Ensure** that children have **access** to health care services in their local community.
- **Provide** an effective and timely **system for referral** to other services the child and his or her family may require, such as Crippled Children's Services, supplemental food programs, or local school district services.
- **Improve communication** between local hospitals, the health department, health care providers, and the schools.



WASHINGTON STATE

HIGH PRIORITY INFANT TRACKING PROGRAM

WASHINGTON STATE
DEPARTMENT OF
SOCIAL & HEALTH
SERVICES

A Program of
The Washington State
Department of Social and Health Services
Mail Stop LC-12A
Olympia, Washington 98504

22-283(X) (Rev. 1986)

Dear Parent,

Your new baby can be part of a program for babies with special needs: The High Priority Infant Tracking Program.

WHAT IS THE HIGH PRIORITY INFANT TRACKING PROGRAM?

Your hospital, physician, nurse and local community health agencies all cooperate to provide the program.

The goals of the program are:

1. To help parents keep their child under the care of a primary physician.
2. To promote early identification of infants requiring further evaluation or services.
3. To assist in planning for the health and educational needs of the children of Washington State.

HOW WILL MY BABY BENEFIT?

Experts in the care of children have learned that some children benefit from close health care follow-up in the early years of life. Such follow-up can prevent health and developmental problems. Your nurse or physician can explain more about how the program will help you and your baby.

HOW DOES THE PROGRAM WORK?

With your permission, the following information will be sent to the program's local coordinating agency:

1. You and your baby's name, address and phone number.
2. Health information about your baby's delivery and hospital stay.
3. The name of the doctor or

health agency who will be caring for your baby after you leave the hospital.

Your doctor or health agency will be contacted periodically to see that your baby continues to receive routine well child care. If you have difficulty obtaining this care, a community health nurse will be available to assist you. Information will be obtained regarding your child's current health and development.

RECOMMENDED SCHEDULE FOR WELL CHILD CARE AND IMMUNIZATIONS

Recommended ages for well child care*	Immunizations
Newborn—2 weeks	
1 month	
2 months	1st DTP, 1st Polio
4 months	2nd DTP, 2nd Polio
6 months	3rd DTP
9 months	
12 months	
15 months	Measles, Mumps, Rubella, 4th DTP, 3rd Polio
18 months	
24 months	Hemophilus b
3 years	
4 years	5th DTP, 4th Polio
5 years	

* each doctor may have a slightly different schedule.

WILL INFORMATION ABOUT MY BABY BE CONFIDENTIAL?

Information about your baby will only be shared with those care providers who need to assist you in getting care for your infant. This includes your doctor, nurse and the local coordinating agency. Local health and social services agencies and your school district may be included with your permission. The State of Washington collects summary information about the program for evaluation purposes. No names of children are given.

DO I HAVE TO GIVE MY PERMISSION?

The program is entirely voluntary. If you do not sign the permission form, your baby will not be enrolled in the program. The care your infant receives will not be affected by your refusal or acceptance of the High Priority Infant Tracking Program.

CAN I WITHDRAW FROM PARTICIPATING LATER?

Yes. If you decide to withdraw your baby from participation, you may do so at any time by notifying your doctor, nurse or contacting your local coordinating agency.

IF I HAVE MORE QUESTIONS ABOUT THE PROGRAM WHO CAN I ASK?

Your baby's doctor or nurse and your local coordinating agency will be able to answer any questions you have about the program.

Your baby's doctor or nurse

____

____

____

We hope you will join us in this project with the overall goal of improving health and development of young children throughout the state.

Thank you,
The Washington State
High Priority Infant
Tracking Program.

Discrimination is prohibited in all programs and activities; no one shall be excluded on the basis of race, color, religion, creed, national origin, sex, age or handicap.

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